University of Alberta

Traumatic Spinal Cord Injury in Alberta: Epidemiology, Health Resource Utilization, and Direct Health Care Costs

by

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requirements for the degree of Doctor of Philosophy

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Abstract

Objectives: 1) To describe the incidence and pattern of traumatic spinal cord injury (SCI) in Alberta, Canada; 2) To document the utilization of health services by persons with SCI; 3) To quantify direct health care costs attributable to SCI.

Methods: For objective 1, population-based data from April 1997 – March 2000 were gathered from 3 provincial sources: the Alberta Ministry of Health and Wellness, Alberta Trauma Registry, and Medical Examiner's Office. For objectives 2 and 3, all persons who sustained a SCI between April 1992 and March 1994 were followed for 6 years. SCI patients were matched (age, sex, region of residence) with persons without SCI randomly selected from the general population. Administrative data were compiled, including hospitalizations, physician contacts, long-term care admissions, and home care services.

Results: The annual incidence rate was 52.5/million population when pre-hospital fatalities were included, and 44.3/million/year when only those who survived to hospital admission were included. Rural residents were 2.5 times more likely to be injured than urban residents. Motor vehicle collisions accounted for 56.4% of injuries, followed by falls (19.1%). Compared with the comparison group, persons with SCI were re-hospitalized 2.6 times more often, spent 3.3 more days in hospital, were 2.7 times more likely to have a physician contact, and required 30 times more hours of home care services. Of those with SCI, 47.6% were treated for a urinary tract infection, 33.8% for pneumonia, and 27.5% for depression. Attributable costs in the first year were $121,600 (2002 $CDN) per person with a complete SCI, and $42,000 per person with an incomplete injury. In the subsequent five years, annual costs were $5,400 and $2,800 for persons with complete and incomplete SCIs, respectively.

Conclusion: Persons with SCI require ongoing follow-up care long after the acute care phase. Direct health costs in the first year post-injury were substantial and in the subsequent 5 years, individuals with SCI continued to accrue greater costs than the comparison group. Primary prevention strategies for SCI should target males of all ages, adolescents and young adults, rural residents, motor vehicle collisions, and fall prevention for those older than 60 years.

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Chapter 1

Introduction

1.1 Overview

The impact of traumatic spinal cord injury (SCI) can be catastrophic, especially when accompanied by permanent loss of motor and sensory function. SCI is usually associated with high mortality (1, 2), severe disability and handicap (3, 4), and prolonged and expensive treatment and rehabilitation (5-7). The primary purpose of this research is to examine the health resource utilization and economic impact of SCI in Alberta using administrative data from the Alberta Ministry of Health and Wellness (8). As a first step to investigating the direct health care costs in the province, it is important to understand the incidence and epidemiology of SCI in Alberta.

This thesis is presented in the paper format, which means that each chapter is presented with its own introduction, methods, results, discussion and set of references. The remainder of Chapter 1 includes a review of the literature on the epidemiology of SCI and on health service utilization and direct health care costs following SCI. This is followed by the rationale for the study and the research objectives. Chapters 2 through 4 are written as stand-alone papers with the intent that they will be submitted for publication[1]. Chapter 2 is a descriptive analysis of the epidemiology of SCI in Alberta. Chapter 3 describes the utilization of health services for six years following SCI in Alberta. Chapter 4 provides cost estimates for direct health care costs attributable to SCI over the first six years post-injury. In Chapter 5, the results of the previous chapters are summarized and discussed in the context of existing research.

1.2 Literature review: Epidemiology of spinal cord injury

1.2.1 Introduction

Because of the high physical, social, and economic impact of traumatic SCI, there is a considerable body of research on the epidemiology of SCI. This review of the literature includes studies from Canada, the United States, Western Europe[2], Australia, and New Zealand. Three electronic databases, Medline and Premedline (1966 – September 2003), EMBASE (1988 – August 2003), and CINAHL (1982 – August 2003), were searched using the subject headings 'spinal cord injuries', 'paraplegia', and 'quadriplegia'. The subheadings 'epidemiology' and 'mortality' were applied to each of the main headings. The search was restricted to English language studies (See Appendix A for search strategies). After removal of duplicate citations, 329 studies were identified from the database searches. Excluded from this literature review were studies that focused on SCI as a result of nontraumatic causes or the result of a specific cause (e.g. sports), studies that examined a single age group (e.g. children), or studies that addressed a particular type or level of SCI (e.g. cervical). Titles and abstracts were scanned by the author to identify exclusions. The result of the screening identified 46 studies that were included in this review. In addition, reference lists were scanned to identify additional sources, including monographs.

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[1] A version of Chapter 2 has been published: Dryden et al 2003. Canadian Journal of Neurological Sciences. 30:113-121. A version of Chapter 3 has been submitted for publication: Dryden et al 2003. Spinal Cord.

1.2.2 Study population

Information on the epidemiology of SCI comes from many different sources and clinical settings. Canadian data (Table 1.1) come from four sources: the Canadian Paraplegic Association (9, 10), the Ontario Trauma Registry (11), hospitals in Ontario (12-14), and a population-based study in Manitoba that examined spinal fractures including those with evidence of SCI (15).

In the United States (Table 1.2), several states have population-based surveillance systems that collect data on SCI (16-22). Some surveillance systems include hospital admissions only, while others include deaths prior to hospitalization. Also in the U.S., there is a large body of literature from the Model Spinal Cord Injuries Care Systems (Model SCI System) (23). At present, the Model SCI System comprises 18 individual centres from across the U.S. that deliver comprehensive, coordinated care for SCI patients. The Model SCI System has maintained a database since 1973 that captures data from an estimated 15% of new SCI cases in the U.S. (24). Other U.S. studies describe the experiences of hospitals or rehabilitation centres in particular states or counties (25-29).

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[2] Countries include Austria, Belgium, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Luxembourg, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, and United Kingdom.

In Western Europe (Table 1.3), data come from single hospitals with SCI or neurology units (30-32), regional rehabilitation centres (33-35), and surveys of hospitals in single regions (36-41). One study from The Netherlands provides information from the national hospital discharge registry (42).

In Australia (Table 1.4), there is a national surveillance system that collects data from six SCI units in the country (43). In New Zealand (Table 1.4), data are derived from the national registry of hospital discharge abstracts (44).

1.2.3 Incidence

In comparing estimates of SCI incidence rates, it is important to consider the inclusion criteria, in particular the inclusion or exclusion of people who died before being admitted to hospital (either at the scene of injury or in the emergency department). In the U.S., studies that include pre-hospital deaths report annual incidence rates between 47 per 1,000,000 population in Utah (21) to 83 per million in Alaska (16). In Portugal, the incidence rate, including pre-hospital deaths, is 58 per 1,000,000 per year (39).

In American studies in which only hospital admissions are included, the incidence rates range from 25 per 1,000,000 in West Virginia (22) to 59 per 1,000,000 in Mississippi (19). In Western Europe, the incidence rates range from 8 per 1,000,000 in Spain (40) to 25 per 1,000,000 in Portugal (39). In Australia, the incidence rate is estimated as 15/1,000,000 and in New Zealand it is 49/1,000,000. In Canada, the Canadian Paraplegic Association estimates the incidence as 35 per 1,000,000 population per year (10). This is within the range reported in a population-based study of SCI in Ontario (46/1,000,000 in 1994/95 and 37/1,000,000 in 1998/99) (11). There is considerable variation in the incidence of SCI across borders and the reason for this variation is unclear.

1.2.4 Age at injury

The mean age at injury has been reported between 20.2 years (26) and 50.5 years (39). However, most studies report a mean age in the mid-30s (14, 16, 18, 25, 31, 36-38). Some investigators have noted a bimodal distribution with the largest peak between 16 and 30 years, and a smaller peak that generally starts at 65 years (25, 27, 29, 31, 39, 44).

The Model SCI System has reported an increase in the mean age at time of injury since 1973, with a pre-1979 mean age of 28.6 years and a post-1990 mean age of 36 years (45). Another trend noted in the Model SCI System is the increase in the proportion of those who were older than 60 years of age at the time of injury. The proportion increased from 4.7% in the 1970's to 11.5% in the 1990s (45). Other studies that collected data over a longer period of time did not report differences in age distribution between the earlier time period (~1950 to 1971) and the later period (1971 to 1980) (14, 27).

1.2.5 Sex

An overwhelming proportion of SCIs occur to males and this finding is consistent across studies (Tables 1.1 – 1.4). The ratio of males to females ranges from 1.5: 1 to 5.5: 1.

1.2.6 Etiology

With few exceptions (11, 29, 31, 42), motor vehicle crashes (MVC) account for the greatest proportion of SCI cases, ranging between 33% (32) and 65% (27) (Table 1.5). Falls generally rank second as the cause of injury. However, the Model SCI System reports that violence-related SCI ranked second (MVC were first) between 1994 and 1998 (45). This is a change from earlier time periods in which falls were ranked second and appears to be unique to this US-based database. In Canada, Western Europe, Australia, New Zealand and the majority of U.S. states, violence-related SCI do not rank higher than fourth on the incidence list (Table 1.5).

1.2.7 Etiology and age

For MVC, the Model SCI System data show a peak at 51% among 16 – 30 year olds, and a gradual decline to 32% among persons over 75 years of age (24, 45). This trend was also reported in France (36) and Portugal (39). In the Model SCI System, fall-related SCI increases steadily from 9% in the 0 – 15 age group to 58% in the 75+ group (24, 45). This pattern has also been reported by others (14, 36, 39, 40). Sports-related injuries are highest in the 0 – 15 year age group (27%) and account for less than 4% of injuries in persons over the age of 46 years (24, 45).

1.2.8 Etiology and sex

For every cause of injury the rate among males is higher than among females. However, the proportion of MVC-related injuries tends to be higher for females (17, 20, 24, 31). Price et al. observed that MVC accounted for 68% of SCIs among females compared with 43% for males (20). There is also a striking difference between males and females in the proportion of sports-related SCIs, which have been reported as 5 – 7% for females versus 14 to 20% among males (24, 31).

1.2.9 Neurological level of SCI

The neurological level of SCI refers to the most caudal segment of the spinal cord with normal sensory and motor function on both sides of the body (46). Persons with tetraplegia have injuries affecting any of the eight cervical spinal nerves. Those with paraplegia have lesions in the thoracic, lumbar or sacral regions of the spinal cord. In studies that included persons who survived to hospital admission, the proportion of patients with tetraplegia ranged from 33% to 71.7%. However, in studies that included injuries sustained only after 1980, the proportion of individuals with tetraplegia ranged from 43.9% to 56.4%. The Canadian Paraplegic Association reports that 47.4% of newly referred clients are classed as having tetraplegia (9).

1.2.10 Extent of SCI

Extent of SCI refers to the extent of neurological damage, which is categorized as either 'complete' or 'incomplete' (46). A complete injury is one in which there is no preservation of any motor or sensory function more than three neurological segments below the point of damage to the spinal cord. An incomplete injury is one in which there is some preservation of motor or sensory function below the lesion. In studies that reported on patients who survived to hospital admission, the proportion of complete injuries ranged from 7.8% to 68.7%. In Canada, Tator et al. reported that 46% of patients had complete injuries (14).

1.2.11 Association between extent and level of injury by etiology

Table 1.6 summarizes data from the Model SCI System that describe the association between level and extent of SCI and the cause of injury (24). Notably, sports-related injuries are most likely to result in tetraplegia, while violence-related injuries result in paraplegia. Falls are more likely to result in incomplete injuries. Other investigators have reported similar associations (12, 33, 36, 43).

1.2.12 Associated injuries

Associated injuries are defined as injuries to other body regions in addition to the SCI. These concomitant injuries can be a major factor in the immediate and long-term outcomes following injury (47, 48). The occurrence of associated injuries has been reported between 19% and 57% depending on the criteria used for inclusion of other injuries (39, 47-49). Associated head injuries range from 11% to 26% of SCI cases and are most frequently seen in conjunction with cervical spine injuries (31, 39, 47, 50, 51). Chest injuries have been reported between 18% and 74% and are associated with thoracic cord lesions (31, 36, 47). Abdominal injuries range from 5% to 30% (31, 36, 47) and fractures to the extremities from 11% to 17% (31, 36, 47).

1.2.13 Mortality

One of the most comprehensive examinations of survival following SCI is by Kraus et al. (1, 25). The authors followed a cohort of 619 persons from northern California who were injured in 1970 or 1971. The cohort was followed for five or six years to December 31, 1976. Of the 619 persons, 235 (38.0%) died at the scene of injury or were dead on arrival at hospital. An additional 64 (10.3%) died during hospitalization. Of the 320 persons who were alive at discharge, 35 (10.9%) died by the end of the study period. Of these, 21 deaths were directly related to the SCI. The overall SCI-specific fatality ratio was 51.7%. Causes of the death for the remainder included seven deaths from cardiovascular disease, five as a result of unintentional injury, and one suicide.

Table 1.7 summarizes studies that include information on deaths early after SCI, i.e. deaths that occurred before or during initial hospitalization. When pre-hospital admission deaths are included, most case fatality rates range from 40.8% (52) to 56.0% (39). The low rate (18.4%) reported by Thurman et al. is likely due to incomplete case ascertainment in the pre-hospital deaths, in particular deaths from multiple severe injuries that may have had undetected SCIs (21). For persons who survive to hospital admission but die during hospitalization, the median case fatality rate is approximately 11% and ranges from 3.6% (16, 18) to 47.6% (39). Most pre-hospital deaths were a result of the initial trauma and included shock-hemorrhage, cardio-respiratory complications, disruption of the spinal cord, and head injuries (1, 53). Leading causes of death among those who survive to hospital admission include respiratory complications, septicemia, and external causes, particularly suicide (1, 34, 54). Early deaths are associated with age at injury and severity of injury, including neurological level, degree of completeness and ventilator dependency (1, 37, 55, 56).

Table 1.8 summarizes reports of longer-term survival (up to 10 years post-injury) for individuals who survived to hospital admission. As a group, people with SCI have reduced life expectancies compared with individuals of similar age and sex in the general population (2, 34, 57, 58). However, studies from the Model SCI System have shown a decline in mortality rates and a corresponding increase in life expectancies among persons with SCI (2, 55, 59). Primary causes of death for late survival are septicemia, pulmonary complications (particularly pneumonia), external causes, heart disease, and pulmonary embolism (2, 34, 54, 59, 60).

1.2.14 Summary

Despite differences in study settings, inclusion criteria, and time periods, findings across studies on the epidemiology of traumatic SCI are remarkably similar. All age groups are affected by SCI, but most injuries occur to young people between the ages of 16 and 30 years. Males are injured more often than females. The most common cause of injury is motor vehicle-related crashes, followed by falls. Approximately 50% of injuries result in tetraplegia. As a group, people with SCI have reduced life expectancies compared with the general population, reported between 77% and 94%. The median case fatality rate for individuals admitted to hospital following their injury is approximately 11% per year, ranging from 3.6% to 47.6%. In Canada, the annual incidence rate has been estimated between 14 and 46/1,000,000 population, which is within the range of incidence rates reported in other countries. Research findings from Canada on the epidemiology of traumatic SCI are reasonably consistent with studies from the U.S., Western Europe, Australia and New Zealand; however, there is a relative paucity of information and some methodological issues that mandate further research on the epidemiology of SCI in Canada.

1.3 Literature review: Utilization of health services

1.3.1 Introduction

This literature review covers research on two key components of the utilization of health services following discharge from initial rehabilitation: hospital readmissions and the utilization of physician services. The focus was to examine the frequency of encounters with the health care system and reasons for contact. The following databases were searched: Medline and Premedline (1966 – September 2003), EMBASE (1988 – August 2003), CINAHL (1982 – August 2003), and Healthstar (1975 – June 2003). Search terms included the subject headings ‘spinal cord injuries’, ‘paraplegia’ and ‘quadriplegia’, combined with subject headings that captured the concepts of ‘re-hospitalization’ and ‘ambulatory care’. Searches were restricted to English language publications (See Appendix A for search strategies). Excluded from this literature review were studies that focused on the clinical care of specific medical conditions or secondary complications. Titles and abstracts were screened to identify exclusions. The result of the screening identified 14 studies that were included in this review. In addition, reference lists were included to identify additional sources, including monographs.

1.3.2 Re-hospitalization

The research on hospital readmissions shows that re-hospitalization is a common occurrence among persons with SCI (Table 1.9). The proportion of people who were re-hospitalized ranged from 25% to 90%, depending on patient population, the length of observation, and the duration of SCI. In a review of Model SCI System records, Ivie et al. reported that each year approximately 30% of patients experienced an unplanned re-hospitalization (76). Persons with SCI are more than twice as likely to be re-hospitalized as a member of the general population in the U.S. (77, 78). For those who are re-hospitalized, the length of stay is three times as long as the general population (78). After the first few years post-injury, the number of re-hospitalizations decrease as do the average lengths of stay (76, 77, 79). The primary reason for hospital re-admission is to treat secondary complications, including urinary tract infections, decubitus ulcers, respiratory infections, and psychosocial disorders (77, 78, 80-83).

1.3.3 Physician services

Few studies have reported on the utilization of physician services by persons with SCI. In a survey of 758 persons with SCI who were at least three years post-injury, Berkowitz et al. found that 86.3% saw a physician at least once a year, with a mean of 18 visits per year (7). In the year prior to the survey, the most commonly visited physicians were urologists (45%), family physicians (44%), neurologists/neurosurgeons (31%), orthopedic surgeons (30%), and physical medicine specialists (27%). Approximately 10% of those surveyed had visited a psychiatrist in the previous year.

Meyers et al. conducted a survey of 96 people with high-level SCI who were between one and 41 years post-injury (82). They found that 78% had seen a physician in the previous year. The median number of outpatient visits to a physician or nurse practitioner in the previous year was 4.0. Almost 50% reported one to five contacts, 39% reported six or more, and 8% reported seeing a physician or nurse practitioner at least once per week.

1.4 Literature review: Cost of spinal cord injury

1.4.1 Introduction

This literature review covers research on direct health care costs of SCI. For the purposes of this review direct health care costs include expenditures associated with the diagnosis and treatment of the injury, including acute hospital care, rehabilitation hospital care, outpatient visits, and physician and non-physician services. Excluded are expenses related to prescription drugs, ambulance services, attendant care, equipment (e.g. wheelchairs), and non-medical expenses such as home modifications or vocational rehabilitation (61).

Literature searches were conducted on the following databases: Medline and Premedline (1966 – September 2003), EMBASE (1988 – August 2003), HealthStar (1975 – June 2003), CINAHL (1982 – August 2003), and EconLit (1969 – June 2003). Search strategies included the subject headings 'spinal cord injuries', 'paraplegia' and 'quadriplegia', combined with subject headings that captured the concept of 'health care costs'. Searches were restricted to English language articles (see Appendix A for search strategies). After removing duplicate citations, the searches resulted in a total of 162 references. Titles and abstracts were screened to exclude reports that reported indirect costs only, focused on specific aspects of care, or reported on the cost effectiveness of treatments or diagnostic procedures. As a result of this screening, 13 studies were included in this literature review. In addition, reference lists were scanned to identify additional references, including monographs.

The results of the studies included in this review are summarized in Tables 1.10, 1.11 and 1.12. The following section reviews the study population and methodology for each study.

1.4.2 Summary of individual studies

Two studies have examined the cost of SCI in Canada. Botterell et al. contacted all hospitals in Ontario to identify patients who were admitted for SCI during 1969 and 1970 (12). Hospital records, including costs, were reviewed for 224 patients. The total cost of hospital care (including initial hospitalization and re-admissions) to the end of 1973 was $2,845,721 (1973 $CDN). This does not include the costs of physician services. The total hospital costs for 115 patients with tetraplegia was $1,612,356 and for 109 patients with paraplegia was $1,233,365. The authors also identified costs incurred by 144 patients who were admitted to hospital for rehabilitation. The total cost for rehabilitation was $1,582,859.

Tator et al. examined the costs for 191 SCI patients admitted to the Acute Spinal Cord Injury Unit (ASCIU) at Sunnybrook Medical Centre, Toronto, Ontario from 1974 to 1981 (62). Costing models were developed to assess the average daily costs of hospital, medical, nursing and rehabilitation during the acute care phase of the hospital stay. Total cost per stay was calculated as the product of length of stay (LOS) and cost per day. The mean cost of the acute care phase was $10,035 (1974 $CDN).

The National Head and Spinal Cord Injury Survey (HSCI Survey) was designed to provide estimates of the incidence and costs of head and spinal cord injury in the U.S. (63, 64). The survey results are based on a probability sample of persons who received inpatient care for a head or spinal cord injury during 1970 through 1974. Cost estimates were determined through personal interviews. The estimates for SCI must be treated with caution because they are not only based on follow-up interviews with only 19 individuals, but also are subject to recall bias. The total direct costs were estimated to be $103 million (1974 $US).

In a retrospective review of the files of two major U.S. insurance companies, Webb et al. studied 85 workers' compensation clients who were injured between 1950 to 1974 (65, 66). The authors reported cost information on the initial hospitalization period (hospitalization from day of injury to the first definitive discharge home) and re-hospitalizations within the first year following injury. The mean first year hospitalization costs were $35,676 (1974 $US). The mean initial hospitalization costs were $28,637 and ranged from $543 to $89,544. Room and board represented 52% of the costs, special services were 35%, and physician services were 11%. The analysis was based on actual charges from general hospitals throughout the U.S. However, given the relatively small sample size, the long time period covered in the data, and the restriction to work-related injuries, it may not be feasible to generalize the results to the SCI population.

Smart and Sanders developed estimates of direct costs in their study of motor vehicle-related SCI (67). Using previous SCI incidence studies, the authors projected that 5,315 motor vehicle-related SCIs would occur in the U.S. in 1974. Based on this projection, SCI impairment rates were calculated for individuals in different age and sex sub-categories. Cost estimates were derived from various SCI centres in the U.S., Canada and Australia. Initial hospitalization costs ranged from a low of $2,300 (1974 $US) for in-hospital fatalities to $15,600 for incomplete paraplegia, and to a high of $38,540 for complete tetraplegia.

A number of studies on costs emanate from the Model SCI System (23). It is important to note that this is not a population-based sample, and there is evidence that the following groups are over-represented in the Model SCI System database: persons with complete tetraplegia, urban dwellers, violence-related injuries, and non-whites (24). Contributions from the Model SCI System include reports from single facilities (68, 69) and those that are an aggregate of data from more than one hospital (5, 70). The most comprehensive study is by DeVivo et al. who conducted a prospective study during 1989 and 1990 (5). A random sample of 508 previous Model SCI System patients and 227 newly injured patients were selected. One year of SCI related medical charge data were collected through telephone interviews and data abstraction. Mean first year costs were approximately $176,000 (1992 $US), ranging from $114,500 to $365,600 depending on severity of injury. The costs included acute care, rehabilitation, re-hospitalization, outpatient services, and physician fees. Mean annual follow-up charges after the first year of injury were $7,300 per person, including hospitalizations, outpatient services, and physician fees. For both first year and annual follow-up, costs for the most severely injured group were higher than the least severely injured group.

In a study of annual follow-up costs, Menter et al. (69) reviewed medical records and conducted telephone interviews with 205 former clients of the Model SCI System centre in Colorado. All participants had complete neurological lesions with no motor or sensory preservation. Patients with incomplete lesions were excluded. Medical expenses were confirmed by contacting the providers utilized during the past year. Follow-up costs ranged from $9,000 to $95,000 per person per year depending on age and level of injury.

In an independent study of the economic consequences of SCI, researchers investigated the costs accrued by a probability sample of 758 SCI persons living in both community and institutional settings in the U.S. (6, 7). Participants responded to a detailed questionnaire that covered the financial, personal and physical impacts of SCI during the first two years post-injury and in the year prior to the interview. Costs were derived from a variety of secondary sources, including government, industry and trade association publications. The authors reported mean hospitalization expenses over the first two years following injury of approximately $95,000 (1988 $US).

In a second survey of SCI costs, Berkowitz et al. (71) surveyed a non-random sample of 363 patients registered with four Model SCI System facilities, plus a random sample of 137 members of the Paralyzed Veterans Association. The sample was restricted to individuals who used a wheelchair as their primary means of getting around. Health care utilization information was provided through interviews in which participants were asked to recall their medical experiences in the previous 12 months. Data from the Model SCI System were used to determine costs. The researchers estimated that the total direct costs of SCI incurred during the first year averaged $223,000 per person (1996 $US), and annual follow-up care averaged more than $9,000.

Using the population-based Oklahoma SCI Registry, Price et al. reported on charges for initial acute hospital care and rehabilitation for 128 individuals who were injured in 1989 (20). Charges for physician fees, outpatient rehabilitation and subsequent hospital admissions were not included, which will lead to an underestimation of the costs. Total charges for the cohort were over $7 million (1989 $US). The combined initial charges ranged from $9,700 to $667,000, with a median cost of $53,400.

Johnson et al. conducted a prospective study with a population-based cohort of 115 Colorado residents identified by the statewide SCI surveillance system in 1989 (72). Cost data for the first two years post-injury were collected through interviews with each participant to determine use of medical services. Billing information was obtained directly from providers. Nearly $22 million (1992 $US) was spent during the first 2 years post-injury. The initial hospitalization phase accounted for $15,454,000 (71%) of total dollars spent. During the period from initial discharge to the first year anniversary of injury $3,258,000 was spent, while $3,015,000 was spent in the second year after injury.

In Australia, cost estimates were established in 1987 through a consensus of the collective experience of Australian experts and published research (73, 74). Initial acute care costs were approximately $60,000 (1987 $Australian), while annual health care costs were $3,000.

1.4.3 Factors associated with costs

Level and severity of injury influence health care costs, with the highest costs associated with complete tetraplegia (Table 1.11). Persons with tetraplegia are likely to be hospitalized longer during the initial hospitalization, and are more likely to be re-hospitalized in subsequent years than those with paraplegia (5, 7, 62, 72). Johnson et al. reported that care provided to persons with tetraplegia accounted for 51% of total costs, 35% was spent providing care to persons with paraplegia, and the remaining 15% was required for care provided to persons with limited neurological impairment (72).

Sex does not appear to influence costs (5, 62, 65, 68), although Berkowitz et al. noted that males incurred higher costs than females over the first two years post-injury and higher annual hospitalization costs (7). They speculated that this was related to the greater severity of injuries incurred by males.

While Charles et al. reported that the youngest (0 – 14 years) and oldest (60+ years) age groups demonstrated lower costs (68), few studies have found that age at injury has a significant impact on costs (5, 62, 65). In their study of follow-up costs, Menter et al. found a statistically significant association between the interaction of age at injury and years since injury (69).

During the acute care phase and the first two years post-injury, secondary complications affect health care costs. Johnson et al. reported that 32.8% of second year follow-up costs were for the treatment of complications, including inpatient, outpatient, and physician charges (72). Fifty-six per cent of the secondary complications required hospitalization. The most frequent complications occurred to the urological and dermatological systems, while the body systems associated with the most expensive complications were neurological, dermatological, respiratory and orthopaedic. During the acute care phase, Tator et al. found that as the number of complications increased, so did costs (62). They reported that pressure sores, respiratory, gastrointestinal, thromboembolic, and genitourinary complications were all associated with increased costs.

Etiology of SCI can also influence costs. Charles et al. observed that motor vehicle-related injuries in the U.S. had higher costs and violence-related injuries were the least expensive (68). In an analysis of the Model SCI System data, DeVivo found differences in costs attributable to each cause of SCI (75). First year charges were highest for sports, followed by vehicle crashes, violence, falls, and 'other causes'. Recurring annual charges were highest for motor vehicle crashes, followed by sports-related injuries, falls, violence, and 'other causes'. The differences in costs are attributed to differences in the nature of injury and population affected. For example, average initial and annual charges are high for sports mishaps because these events occur among younger persons and almost always result in tetraplegia. Initial charges are lowest for falls because they often result in incomplete neurological injuries. However, annual charges rank third for falls because they typically occur among the elderly who are more likely to need attendant care and nursing home services.

DeVivo et al. conducted a multivariable analysis to identify predictors of first year costs for patients admitted to Model SCI System centres (5). They found that injury severity, ventilator dependence, nursing home stay, re-hospitalizations, complications, and attendant care during the year were significant predictors of costs. In examining predictors of follow-up costs after the first year, the authors identified injury severity, ventilator dependence, nursing home stay, re-hospitalization, and attendant care as significant predictors (5). In a Canadian study, Tator et al. also used multivariable analysis to identify factors associated with length of stay and costs during the acute care phase (62). They found that secondary complications, delay in admission to the spinal injury unit, and severity of injury were significant factors.

1.4.4 Summary

This literature review on the cost of SCI highlights a number of issues. Comparisons across studies are difficult because of different time periods, study populations, definitions of SCI, etiologies, items included in cost estimates, and costing methods used. Many cost studies are limited by use of a select population such as persons admitted to a particular hospital (62, 68), insured by a specific provider (65, 66), injured from a single cause (65-67) or with a specific neurological impairment (69, 71). In some studies the cost estimates have been derived from secondary sources that may not reflect actual costs or charges (7, 67, 73). Some studies are subject to recall bias where cost and/or utilization data were collected through interviews with persons with SCI (5, 7, 63, 71, 72). Not only are there differences in cost estimates across studies, but also there is considerable variability in individual cost estimates. This is primarily a reflection of the diversity of the SCI population, in particular the severity of injury to the spinal cord.

While these studies have contributed to our understanding of costs associated with SCI, it is difficult to generalize the results to other settings or populations of persons with SCI. Nevertheless, the following observations can be made. The direct health care costs associated with SCI are enormous. In the population-based study by Johnson et al., direct costs in the first two years following injury for 115 individuals were approximately $21 million (1992 $US) (72). The initial hospitalization phase accounted for $15 million or 71% of the total dollars spent over two years. From the studies included in this review, the mean initial hospitalization costs ranged from $17,500 (1974 $US) (67) to $195,000 (1996 $US) (71) (Table 1.10). Mean annual costs after the initial period of recovery and rehabilitation ranged from $5,800 (1988 $US) (7) to $9,000 (1996 $US) (71) (Table 1.12).

1.5 Study rationale

The literature review has provided a basis for the current research. While there is a substantive body of international literature on the epidemiology of SCI, there is limited Canadian research on the topic. Many of the Canadian studies are dated or are not population-based and, therefore, may not reflect the current situation in Alberta. Similarly, there is limited Canadian data on the health care costs of SCI, and no information on the costs beyond the initial hospitalization phase. It may not be appropriate to generalize research from other countries to a Canadian setting in part due to methodological deficiencies of previous studies, but also because of differences in access to health care.

Chapter 2 describes the incidence and pattern of traumatic SCI in Alberta using data from three provincial sources: the Alberta Ministry of Health and Wellness, the Alberta Trauma Registry, and the Office of the Medical Examiner. Chapters 3 and 4 examine health care utilization and costs following SCI using administrative data from the Alberta Ministry of Health and Wellness. This population-based cohort study follows individuals with SCI from date of injury to six years post-injury. Access to such accurate and comprehensive data has not previously been available in other studies. The results of this research will help guide resource utilization for the provision of health services for SCI. More importantly, they can be used to encourage government and regional health authorities to reduce costs associated with SCI by implementing appropriate primary and secondary prevention activities.

1.6 Research objectives

The objectives of this research are:

1) To describe the epidemiology of SCI in Alberta, including persons who died at the scene of injury and those who survived to hospitalization;
2) To describe the utilization of health services following SCI from date of injury to six years post-injury;
3) To compare the utilization of health services by persons with SCI with that of the general population;
4) To quantify the direct health care costs following SCI from date of injury to six years post-injury.

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Table 1.1. Summary of studies on the epidemiology of traumatic SCI in Canada.

Author, Date	Study population	Data source	Study period	No. of cases	Annual Incidence Rate/million	Male: Female ratio	Age	Level of SCI (% Tetraplegia)	Extent of SCI (% Complete)
Botterell, 1975 (12)	Admissions to hospitals in Ontario	Chart review	1969/70	224	14 – 16	4.6: 1	Not given	51.3%	36.6%
Tator, 1979 (13)	Admissions to 2 hospitals in Toronto	Chart review	1948/73	358	Not given	4.5: 1	Median 32 yrs	56.7%	65.0%
Tator, 1993 (14)	Admissions to SCI unit in Toronto	Chart review	1974/81	201	Not given	3.9: 1	Mean 34.5 yrs	63.2%	46.2%
Hu, 1996 (15)	Admissions to hospitals in Manitoba	Administrative data	Apr 1981 – Mar 1984	122	40	Not given	Not given	35.6%	Not given
Canadian Paraplegic Association, 1997 (9)	Survey of Canadians injured for at least 5 yrs	Questionnaire	1995	966	35	4.3: 1	Not given	47.4%	Not given
Pickett, 2003 (11)	Admissions to hospitals in Ontario	Ontario Trauma Registry	1994/95 – 1998/99	2,385	46 (1994/95) – 37 (1998/99)	Not given	Not given	Not given	Not given

Table 1.2. Summary of studies on the epidemiology of traumatic SCI in the United States.

Author, Date	State	Study population	Data source	Study period	No. of cases	Annual Incidence Rate/million	Male: Female ratio	Age	Level of SCI (% Tetraplegia)	Extent of SCI (% Complete)
Go, 1995 (24)	United States	Model SCI System	Model SCI System database	1973/92	14,791	N/A	4.6: 1	Mean 30.7 yrs	52.9%	48.3%
Warren, 1995 (16)	Alaska	Surveillance system; Hospital admissions & DOA	Trauma registry	1991/93	139	83	5.1: 1	Median 33 yrs (11 – 85 yrs)	43.9%	6.5%
Acton, 1993 (17)	Arkansas	Surveillance system; Hospital admissions	SCI registry	1980/89	644	9	4.1: 1	Mean M=32.4 yrs F=35.4 yrs	43.9%	32.9%
Kraus, 1975 (25)	Northern California (18 counties)	Hospital admissions & pre-hospital deaths	Chart review Autopsy reports	1970/71	619	53 or 32 for hosp. admissions	2.9: 1	Mean M=34.4 yrs F= 36.2 yrs	24.7%	22.2%
Gerhart, 1991 (18)	Colorado	Surveillance system; Hospital admissions	Chart review Interviews	1986/99	358	24 – 30	3.8: 1	Mean 35 yrs	52%	34.9%
Goebert, 1991 (26)	Hawaii	Admissions to 1 rehab centre	Chart review	1987/89	59	28	5.5: 1	Mean 20.2 yrs	62.1%	50.8%
Griffin, 1985 (27)	Minnesota (1 county)	Hospital admissions & pre-hospital deaths	Chart review Autopsy reports	1935/81	154	55 or 34 for hosp. admissions	2.6: 1	Not given	56.5%	Not given

Table 1.2. Summary of studies on the epidemiology of traumatic SCI in the United States (continued).

Author, Date	**State**	**Study population**	**Data source**	**Study period**	**No. of cases**	**Annual Incidence Rate/million**	**Male: Female ratio**	**Age**	**Level of SCI (% Tetraplegia)**	**Extent of SCI (% Complete)**
Surkin, 2000 (19)	Mississippi	Surveillance system; Hospital admissions & pre-hospital deaths	Chart review Death certificates	1992/94	395	77 or 59 for hosp. admissions	4.0: 1	Not given	52.3%	Not given
Relethford 1991 (28)	New York	Hospital admissions	Hospital discharge data	1982/88	5,384	43	Not given	Not given	Not given	Not given
Price, 1994 (20)	Oklahoma	Surveillance system; Hospital admissions	Chart review	1988/90	376	40	3.9: 1	From 2 – 88 yrs	56.4%	30.3%
Buechner, 2000 (29)	Rhode Island	Hospital admissions	Chart review	1993/98	277	56	Not given	Not given	Not given	Not given
Thurman, 1994 (21)	Utah	Surveillance system; Hospital admissions & pre-hospital deaths	Chart review Death certificates	1989/91	223	47	3.2: 1	Median 29 yrs	57.4%	Not given
Woodruff, 1994 (22)	West Virginia	Surveillance system; Hospital admissions	SCI registry	1985/88	143	25	4.6: 1	Not given	Not given	Not given

Table 1.3. Summary of studies on the epidemiology of traumatic SCI in Western Europe.

Author, Date	Country	Study population	Data source	Study period	No. of cases	Annual Incidence Rate/million	Male: Female ratio	Age	Level of SCI (% Tetraplegia)	Extent of SCI (% Complete)
Biering-Sorensen, 1990 (33)	Denmark	Admissions to 1 rehab centre	Chart review	1975/84	268	9	3.3: 1	Not given	50.7%	48.1%
Minaire, 1978-79 (36)	France (1 region)	Hospital admissions	Chart review	1970/75	351	13	3.7: 1	Mean 39 yrs	Not given	Not given
Daverat, 1989 (37)	France	Admissions to 1 hospital	Chart review	1982/ July 1985	157	Not given	4: 1	Mean 38 yrs (5 - 86 yrs)	52%	Not given
Knutsdottir, 1993 (30)	Iceland	Admissions to 1 rehab unit	Chart review	1973/82	45	Not given	2.2: 1	Not given	55.6%	29%
Palma, 1992 (31)	Italy	Admissions to 1 Neuro Dept.	Chart review	1980/90	233	Not given	4.8: 1	Mean 37.1 ± 17.1 yrs	71.7%	68.7%
Schonherr, 1996 (35)	Nether-lands	Admissions to 1 rehab centre	Chart review	1982/93	142	8	3.3: 1	Mean 45.1 yrs	46.5%	40.8%
Van Asbeck, 2000 (42)	Nether-lands	Natl. Registry search	Chart review	1994	113	12	3.3: 1	Not given	57.5%	48.7%
Gjone, 1978-79 (38)	Norway	Admissions to 37 hospitals	Chart review	1974/75	131	17	5.0: 1	Mean 37 yrs	52.7%	43.5%
Martins, 1998 (39)	Portugal (1 region)	Hospital admissions & pre-hospital deaths	Chart review	1989/92	398	58 or 25 for hosp. admissions	3.4: 1	Mean 50.5 yrs	Not given	55.6%
Garcia-Reneses, 1991 (40)	Spain	Admissions to 13 hospitals	Chart review	1984/85	616	8	Not given	Not given	Not given	Not given
Gehrig, 1968-69 (41)	Switzer-land	Admissions to 65 hospitals	Chart review	1960/67	584	13	1.5: 1	Range 1 – 80+ yrs	33%	Not given
Kuhn, 1983 (32)	Switzer-land	Admissions to 1 SCI centre	Chart review	1979/81	330	Not given	2.6: 1	Not given	41.5%	Not given

Table 1.4. Summary of studies on the epidemiology of traumatic SCI in Australia and New Zealand.

Author, Date	**Country**	**Study population**	**Data source**	**Study period**	**No. of cases**	**Annual Incidence Rate/million**	**Male: Female ratio**	**Age**	**Level of SCI (% Tetraplegia)**	**Extent of SCI (% Complete)**
O'Connor, 1998 (43)	Australia	Surveillance system; 6 SCI units	SCI registry	1998/99	265	15	3.2: 1	Not given	57.7%	37.4%
Dixon, 1993 (44)	New Zealand	National hospital discharge abstract (806x + 952x)	Administrative data	1988	164	49	Not given	Not given	42.9%	7.8%

Table 1.5. Etiology of traumatic SCI.

Author, date	Location	MVC (%)	Falls (%)	Sports (%)	Intentional (%)	Other (%)
O'Connor, 1998 (43)	Australia	42.6	31.3	13.2	5.0	Other 7.9
Tator, 1979 (13)	Canada	34.4	23.7	15.4	Violence 1.4 Suicide 1.4	Struck 12.3 Other 11.4
Pickett, 2003 (11)	Canada	42.8	43.2	Not given	Violence 2.3 Suicide 1.4	Struck 6.5 Other 3.9
Biering-Sorensen, 1990 (33)	Denmark	46.6	26.1	11.2	Violence 1.9 Suicide 7.8	Struck by object 5.2 Other 1.2
Minaire, 1978-79 (36)	France	47.2	28.6	7.8	Gunshot 0.8	Struck by object 7.5 Other 8.1
Knutsdottir, 1993 (30)	Iceland	50	37			Other 13
Palma, 1992 (31)	Italy	30.5	12.9	17.5	Firearms 6.9	Occupational 32.2
Van Asbeck, 2000 (42)	Netherlands	31.0	48.7	8.9		Other 11.4
Dixon, 1993 (44)	New Zealand	54	24	11	2	Other 8
Martins, 1998 (39)	Portugal	57.3	37.4			Other 5.3
Garcia-Reneses, 1991 (40)	Spain	52.2	27.4	3.2	Projectile 3.2	Other 14.0
Gehrig, 1968-69 (41)	Switzerland	36	35 (Work related)	29 (Home & sports)		
Warren, 1995 (16)	U.S.: Alaska	52.5	21.6	4.3	1.4	Other 20.1
Acton, 1993 (17)	U.S.: Arkansas	49.5	13.4	11.3	11.2	Struck by object 5.3 Other 9.0
Kraus, 1975 (25)	U.S.: California	55.9	19.2	7.0	12.0	Other 6.0
Gerhart, 1991 (18)	U.S.: Colorado	55.6	19.0	8.7	6.0	Struck by object 4.0 Other 6.0
Griffin, 1985 (27)	U.S.: Minnesota	65.6	13.0	7.8	3.2	Occupational 7.1 Other 3.2
Surkin, 2000 (19)	U.S.: Mississippi	58.2	12.9	3.5	15.7	Struck by object 3.5 Other 6.7
Price, 1994 (20)	U.S.: Oklahoma	50.2	19.9	12.7	11.2	Struck by object 4.3 Other 1.6
Buechner, 2000 (29)	U.S.: Rhode Island	29	39		13	Other 19
Thurman, 1994 (21)	U.S.: Utah	49.3	21.1	15.7	5.4	Other 8.5

Table 1.6. Association between extent and level of injury and etiology (Model SCI System 1994-98) (24).

Neurological Category	MVC	Falls	Sports	Violence
Complete tetraplegia (%)	32.0	17.7	44.0	17.4
Incomplete tetraplegia (%)	24.6	36.3	45.1	13.8
Complete paraplegia (%)	25.7	22.8	5.4	42.2
Incomplete paraplegia (%)	17.1	22.2	4.9	26.4
No deficit (%)	0.6	1.0	0.6	0.2

Table 1.7. Deaths from time of injury to discharge from hospital.

Author / Publication year	Location / Study period	Study population (A)	Deaths prior to hospital admission (B)	In hospital deaths (C)	All Deaths (B + C)	Case fatality rate for all deaths (B + C / A)	No. admitted to hospital (D)	Case fatality rate for those admitted to hospital (C / D)
Tator, 1979 (13)	Canada, 1974/81	201	Not given	14		N/A	201	7.0%
Van Asbeck, 2000 (42)	Netherlands, 1994	126	Not given	18		N/A	126	14.3%
Martins, 1998 (39)	Portugal, 1989/92	398	64 (16.1%)	159	223	56.0%	334	47.6%
Warren, 1995 (16)	Alaska, 1991/93	139	Not given	5		N/A	139	3.6%
Kraus, 1979 (1)	California, 1970/71	619	235 (38.0%)	64	299	48.3%	384	16.7%
Gerhart, 1991 (18)	Colorado, 1986/89	358	Not given	13		N/A	358	3.6%
Griffin, 1985 (52)	Minnesota, 1935/81	154	58 (37.7%)	11	69	44.8%	95	11.6%
Surkin, 2000 (19)	Mississippi, 1992/94	395	91 (23.0%)	70	161	40.8%	304	23.0%
Price, 1994 (20)	Oklahoma, 1988/90	376	Not given	30		N/A	376	8.0%
Thurman, 1994 (21)	Utah, 1989/91	223	21 (9.4%)	20	41	18.4%	202	9.9%

Table 1.8. Survival probabilities for persons with SCI.

Author/ Publication Year	Study location	Injury period/ End of follow-up	Inclusion criteria	Survival period	Cases (Deaths)	Survival probabilities
DeVivo, 1987 (55)	Model SCI System	1973 – 1980 / followed to Dec. 1981	Survived 24 hours after injury	7 years	5,131 (459)	86.7%
DeVivo, 1992 (2)	Model SCI System	1973 – 1984 / followed to Dec. 1985	Survived 24 hours after injury	7 years 10 years	9,135 (854)	89.2% 86.4%
DeVivo, 1992 (60)	Model SCI System	1973 – 1986	Survived 24 hours after injury	2 years	1,898	1973-77 90.0% 1978-80 90.4% 1981-83 92.1% 1984-86 94.1%
Griffin, 1985 (27)	Minnesota	1935 – 1981 / followed to Dec. 1981	Survived 24 hours after injury	10 years	95 (58)	77%
Kraus, 1979 (1)	Northern California	1970 & 1971 / followed to Dec. 1976	Survived 24 hours after injury	5 to 6 years	367 (47)	84%
Mesard, 1978 (56)	Washington, DC	1955 – 1965 / followed to June 1967	White male veterans treated in VA hospital; survived the first 3 mos.	10 years	2,323 (1,276)	Paraplegia 86% Tetraplegia 80%
McColl, 1997 (57)	Ontario	1945 –1990 / followed to Dec. 1991	Aged 25 - 34 yr at injury; treated at 2 rehabilitation hospitals; survived 1 yr. after injury	10 years	606 (142)	92.6%
Hartkopp, 1997 (34)	Denmark	1953 – 1990 / followed to Dec. 1992	Survived to admission to a rehabilitation hospital	7 years	888 (236)	1953-71 87.6% 1972-90 90.7%
Burke, 1960 (58)	Veterans Administration hospitals in U.S.	1946 – 1955 / followed to Oct. 1956	Aged less than 60 yr at time of injury; veterans treated in VA hospital; survived 1-yr after injury	10 years	5,575 (not given)	77%

Table 1.9. Summary of studies on re-hospitalization after discharge from initial hospitalization.

Author, date	**Study setting; Study population**	**Data source**	**No. cases**	**Duration of injury**	**Re-hosp (No. (%))**	**Length of stay**	**Reasons for hospitalization**
Meyers, 1985 (82)	Massachusetts; Persons with tetraplegia using a wheelchair	Interviews about health care use in previous year	96	1 – 41 years	57%	Mean =16 days/person-year	Respiratory infection 19% Further rehab. 16% UTI 14% Decubitus ulcer 9%
Meyers, 1989 (84)	Massachusetts; Persons with tetraplegia using a wheelchair	Monthly telephone interviews over 18 month follow-up	87	Mean= 9.2 years	66 (75.8%)	Not given	Infections 41% Surgical procedure 13% Physical exam 11%
Davidoff, 1990 (80)	Model SCI System; persons injured between 1983 & 1987	Medical records from date of discharge to first year post-injury	88	1 year post discharge from initial hospitalization	34 (38.6%); 47 admissions	Mean=11.9 days	UTI 17% Further rehab. 19% Venous thromboembolism 13% Spinal surgery 13% Decubitus ulcer 4%
Berkowitz, 1992 (7)	Probability sample of persons with SCI in U.S.	Interviews about health care use in previous year	758	At least 3 years post-injury	28.9%	Mean=6.6 days	Not given
Ivie, 1994 (76)	Model SCI System; Persons injured between 1986 & 1992	Interviews at annual assessment about health care use in previous year	2,305	1 – 7 years	604 (26.2%)	Mean=11.6 days	Not given
Samsa, 1996 (79)	Veterans Hospitals in U.S.; Male veterans	Administrative data	1,250	1 – 15 years	1,127 (90%); 1.9 admissions/person-yr. in Year 1; 0.6 admissions/person-yr in Year 15	Median=10 days	Not given

Table 1.9. Summary of studies on re-hospitalization after discharge from initial hospitalization (continued).

Johnson, 1998 (77)	Colorado; Persons injured between 1986 & 1993	Telephone interviews at first, third & fifth year post-injury	170	1 year at beginning of study	27.2% Year 1 20.1% Year 3 18.8% Year 5	Not given	For those with LOS > 2 wks: Decubitus ulcer Respiratory complic. Spinal surgery
Vaidyanathan, 1998 (85)	United Kingdom; Persons with tetraplegia admitted to spinal injury centre in 1994 & 1995	Hospital records	Not given	Not given	221 admissions by 155 people	3,260 days over 2 years	Urinary tract related 43.4% Cardio-respiratory 23.1% Neurological 8.1% Gastrointestinal 7.7%
Noreau, 2000 (81)	Quebec; Random sample of persons with SCI	Mail questionnaire about health care use in previous year	482	2 – 26 years	24.2%	Not given	UTI 54% Decubitus ulcer 26% Pain 15% Spasticity 11% Gastrointestinal 11%
Savic, 2000 (78)	United Kingdom; Patients admitted to spinal injury centre	Interviews and medical records for hospital admissions between 1990 & 1996	198	20+ years	127 (64.1%); 481 admissions	Mean=12.0days	UTI 41% Decubitus ulcer 17% Digestive system 11% Muskuoloskeletal 9% Nervous system 7%
Klotz, 2002 (83)	France; Persons with tetraplegia admitted to a participating rehab centre	Self-administered questionnaire	1,668	2 – 40 years	74.4% Median= 3/person	Not given	UTI 32% Follow-up 28% Decubitus ulcer 20% Respiratory complic. 14% Contractures 10%

Table 1.10. Estimates of direct health care costs during initial hospitalization, including acute & rehabilitation care to first definitive discharge home.

Author / Publication Year	Currency	Study population / Study period	Cost Ascertainment	Acute Care Costs (Mean)	Acute Care LOS (Mean)	Rehab. Costs (Mean)	Rehab. LOS (Mean)	Initial hospitalization Costs (Mean)	Initial hospitalization LOS (Mean)
Botterell, 1975 (12)	1973 $CDN	N=144; Patients admitted for rehab. to Ontario hospitals in 1969 & 1970	Cost estimates from hospitals; Excludes physician fees	Not given	Not given	$10,992	244 days	N/A	N/A
Tator, 1993 (62)	1974 $CDN	N=191; Patients admitted to the ASCIU, Toronto, ON between 1974 & 1981	Costing model estimated average costs per day for SCI patients	$10,035	49.8 days	Not given	Not given	N/A	N/A
Kalsbeek, 1980 (63)	1974 $US	Estimates for U.S. SCI population for 1974 (from the HSCI survey)	Interviews	$3,900	Not given	Not given	Not given	N/A	N/A
Smart & Sanders, 1976 (67)	1974 $US	Based on a projection of 5315 motor vehicle-related SCIs in the US in 1974	Estimates based on costs from Model SCI System centres	Not given	Not given	Not given	Not given	$17,500	111 days
Webb, 1977 (65); Webb, 1979 (66)	1974 $US	N=85; Work-related injuries between 1950 & 1974	Workman's Compensation files at 2 insurance companies	Not given	Not given	Not given	Not given	$29,025 ± $18,809	184 days

Table 1.10. Estimates of direct health care costs during initial hospitalization, including acute & rehabilitation care to first definitive discharge home (continued).

Author / Publication Year	**Currency**	**Study population / Study period**	**Cost Ascertainment**	**Acute Care Costs (Mean)**	**Acute Care LOS (Mean)**	**Rehab. Costs (Mean)**	**Rehab. LOS (Mean)**	**Initial hospitalization Costs (Mean)**	**Initial hospitalization LOS (Mean)**
Charles, 1977-78, (68)	1976 $US	N=142; Patients admitted to the Model SCI System centre in Birmingham, Alabama between 1972 & 1976	Billed charges	$7,780 ± $6516	34 ± 23 days	$11,624 ± $6,516	74 ± 42 days	$19,382 ±10,589	108 ± 49 days
Young, 1978 (70)	1976 $US	N=132; Patients treated at 11 Model SCI System centres during 1976	Billed charges	Not given	Not given	Not given	Not given	$31,337 ± $16,726	Not given
Harvey, 1992 (6); Berkowitz, 1992 (7)	1988 $US	N=758; Representative sample of the U.S. SCI population living in community & institutions; survey conducted in 1988 & 1989	Interviews identified medical services used in previous year; Costs derived from secondary sources	Not given	Not given	Not given	Not given	$95,203* *First 2-years post-injury	171 days* *First 2-years post-injury
Price, 1994 (20)	1989 $US	N=128; Oklahoma SCI surveillance system; patients injured in 1989	Billed charges; Excludes physician fees	Median costs from $16,961 – $69,201	Median LOS from 36 – 52 days	Median costs from $18,253 - $27,184	Median LOS from 13 – 34 days	Median = $53,410 ranging from $9,790 – $666,510	Not given

Table 1.10. Estimates of direct health care costs during initial hospitalization, including acute & rehabilitation care to first definitive discharge home (continued).

Author / Publication Year	Currency	Study population / Study period	Cost Ascertainment	Acute Care Costs (Mean)	Acute Care LOS (Mean)	Rehab. Costs (Mean)	Rehab. LOS (Mean)	Initial hospitalization Costs (Mean)	Initial hospitalization LOS (Mean)
DeVivo, 1995 (5)	1992 $US	N=227; Patients admitted to Model SCI System centres between 1973 & 1989	Billed charges	$67,601	24.9 days ranging from 18 – 46 days	$95,810	77.5 days ranging from 56 – 116 days	$163,411	102.4 days
Johnson, 1996 (72)	1992 $US	N=115; Colorado SCI surveillance system; patients injured in 1989	Interviews & billed charges	$69,948	Not given	$62,933	Not given	$132,881	Not given
Berkowitz, 1998 (71)	1996 $US	N=500; Sample of US SCI population; interviewed in 1996	From Model SCI System cost estimates	$89,410	20.4 days ranging from 13.5 – 26.8 days	$106,271	54.2 days ranging from 38.1 – 77.7 days	$195,681	74.6 days

Table 1.11. Estimates of direct health care costs of SCI by level and severity of injury.

Author/ Publication year	Currency	Tetraplegia (Mean cost)	Paraplegia (Mean cost)	Minimal impairment (Mean cost)	Notes
Botterell, 1975 (12)	1973 $CDN	Complete $18,999 Incomplete $12,265	Complete $10,135 Incomplete $5,964	N/A	Rehabilitation care only
Tator, 1993 (62)	1974 $CDN	$10,342 (complete & incomplete)	$9,800 (complete & incomplete)	N/A	Acute care phase only
Webb, 1977 (65); Webb, 1979 (66)	1974 $US	$42,240 (complete & incomplete)	$32,619 (complete & incomplete)	N/A	All hospitalizations in first year post-injury Work-related injuries
Charles, 1977-78 (68)	1976 $US	$19,887 (complete & incomplete)	$18,944 (complete & incomplete)	N/A	Initial hospitalization* Model SCI System
Young, 1978 (70)	1976 $US	Complete $42,720 Incomplete $32,846	Complete $26,911 Incomplete $19,196	N/A	Initial hospitalization* Model SCI System
Griffiths, 1987 (73); Walsh, 1988 (74)	1987 $Australian	$110,000 (complete & incomplete)	$64,000 (complete & incomplete)	N/A	Initial hospitalization* Cost estimates based on consensus
Harvey, 1992 (6); Berkowitz, 1992 (7)	1988 $US	Complete $136,029 Incomplete $115,028	Complete $101,537 Incomplete $65,955	N/A	Hospital costs in first 2-years post-injury including rehabilitation
DeVivo, 1995 (5)	1992 $US	C1-C4 $365,890 C5-C8 $167,764 (complete & incomplete)	T1-S5 $136,219 (complete & incomplete)	$115,321	First year costs Model SCI System
Johnson, 1996 (72)	1992 $US	C1-C4 $263,610 C5-C8 $285,430 (complete & incomplete)	T1-S5 $160,336 (complete & incomplete)	$50,964	Initial hospitalization Population-based
Berkowitz, 1998 (71)	1996 $US	$339,965 (complete & incomplete)	$174,007 (complete & incomplete)	$144,294	First year costs

* Initial hospitalization includes acute & rehabilitation care to first definitive discharge to home.

Table 1.12. Estimates of annual follow-up direct health care costs following SCI.

Study	Currency	Study population	Mean annual costs (± SD)	Notes
Smart & Sanders, 1976 (67)	1974 $US	Based on projection of 5,315 motor vehicle-related SCIs	$2,460 (tetraplegia) $300 to $1,500 (paraplegia)	Annual re-hospitalization costs
Webb, 1977 (65); Webb, 1979 (66)	1974 $US	N=85; Work-related injuries	$6,651 (±7,131) (median = $3,259)	Re-hospitalizations in the first year after initial discharge
Harvey, 1992 (6); Berkowitz, 1992 (7)	1988 $US	N=758; Representative sample of US SCI population	Hospitalization: $3,479 Professional fees: $2,334	Annual costs after initial period of recovery
Menter, 1991 (69)	Not given	N=205 Patients at the Model SCI System centre in Colorado	From $9000 to $95,000 per year depending on level of injury	Annual costs after initial period of recovery Hospitalization, physician costs, attendant care Includes patients with complete lesions only
DeVivo, 1995 (5)	1992 $US	N=508; Model SCI System	Hospitalization: $5,255 Outpatient: $1,032 Professional fees: $322	Annual costs after the first year post-injury
Johnson, 1996 (72)	1992 $US	N=106; Colorado SCI surveillance system	Hospitalization: $6,247 Outpatient: $2,550 Professional fees: $2,000	Costs in the second year post-injury
Berkowitz, 1998 (71)	1996 $US	N=500; Representative sample of US SCI population	Hospitalization: $7,665 Professional fees: $1,342	Annual costs after the first year post-injury Individuals who use wheelchairs for ambulation

Chapter 2

The Epidemiology of Traumatic Spinal Cord Injury in Alberta, Canada[3]

2.1 Introduction

The impact of traumatic spinal cord injury (SCI) can be catastrophic, especially when accompanied by permanent loss of motor and sensory function. SCI is usually associated with high mortality (1, 2), severe disability and handicap (3-5), and prolonged and expensive treatment and rehabilitation (6-9). Reported annual incidence rates in North America range from 25 to 93 per million population (10-16), with the highest incidence occurring among males, and adolescents and young adults (12, 13, 15, 17-19). The leading causes of SCI are motor vehicle collisions (MVC), falls, violence, and sports activities (12-15, 17-19). Since there is currently no cure for SCI, primary prevention efforts are important. In order to identify risk factors and implement targeted prevention strategies, it is necessary to determine the incidence, cause and circumstances that resulted in injury.

To date there has been limited research on the epidemiology of SCI in Canada. In a survey conducted in 1969 and 1970, Botterell et al. estimated the incidence of SCI in Ontario as 13 and 16 per million population per year, respectively (20). A population-based study in Ontario used data from the Ontario Trauma Registry to identify SCI-related, acute care hospitalizations during fiscal years 1994-95 through 1998-99 (14). The annual incidence rates ranged from 37.3 per million (1998-99) to 46.2 per million (1994-95). The Canadian Paraplegic Association estimates that the current annual SCI incidence rate in Canada is 35 cases per million population (11).

Tator et al. provided a detailed description of 201 consecutive patients admitted to the Acute Spinal Cord Injury Unit (ASCIU) at Sunnybrook Medical Centre in Toronto, Ontario between 1974 and 1981 (21, 22). Most patients were male (79.6%) and the median age at injury was 27.0 years. Motor vehicle collisions were the greatest cause of injury (40.8%), followed by sports and recreational activities (22.9%), and work-related incidents (13.9%). Injuries at the cervical level were most frequent (63.2%). Injuries at the thoracic level occurred in 16.9% of cases and at the thoracolumbar region in 19.9%. Lesions were classed as complete for 46.2% of individuals.

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[3] A version of this chapter has been published: Dryden et al 2003. Canadian Journal of Neurological Sciences. 30: 113-121.

Hu et al. conducted a population-based study on spinal fractures in Manitoba (23). The researchers analyzed administrative data from the Manitoba Health Service Insurance Plan for persons who sustained a spinal fracture between April 1, 1981 and March 31, 1984. Of the 122 individuals who suffered a spinal fracture with spinal cord involvement, 34.4% sustained an injury at the cervical level, 38.5% at the thoracic level, and 23.8% at the lumbosacral level. The SCI was unspecified for the remainder (3.3%). No information was given on the etiology of SCI.

The Canadian Paraplegic Association conducted a survey in 1995 – 1996 of a random sample of 966 Canadians with SCI who had been injured for at least five years (24). A majority of the survey participants were male (81%). More than half were injured between the ages of 15 and 24 years, and 78% between 15 and 34 years. The participants reported that 47.4% of injuries were at the cervical level.

In the review of data from the Ontario Trauma Registry, there were 2,385 hospital admissions for SCI over the five-year study period (14). Males experienced 68.4% of injuries. Falls and transport-related incidents, including motor vehicle, non-motorized road vehicle and other transport incidents, were the most common causes of injury (43.2% and 42.8%, respectively).

The results of these Canadian studies on the epidemiology of SCI are reasonably consistent with reports from other countries in terms of demographics and etiology (12, 13, 19, 25, 26). However, studies that are hospital or institution-based may result in referral bias (22, 24, 27). The Manitoba study that included only patients with a vertebral fracture associated with their SCI includes only a segment of the SCI population (23). The Ontario study by Pickett et al. (14) is the most current and comprehensive study to date. However, as with other Canadian studies, people who died at the scene of injury or who were dead on arrival at hospital have been excluded (14, 22, 23, 27). The results of these studies will underestimate of the magnitude of the problem and may miss important differences in the etiology of SCI (12, 13, 19).

The following research presents the results of a population-based study from the province of Alberta, Canada. The study population includes people who died at the scene of injury as well as those who were hospitalized for SCI. The goal of this research was to fully describe the epidemiology of SCI in a well-defined region for which data are available. Specific questions addressed were: 1) What was the incidence of SCI between April 1, 1997 and March 31, 2000?; 2) What was the occurrence of SCI by age, sex, severity of injury and cause?; and 3) What risk factors contributed to the occurrence of SCI?

2.2 Methods

2.2.1 Study location

Alberta is located in western Canada and occupies an area of approximately 661,000 square kilometres. In 1998 the population was estimated as 2.8 million, of which 80% lived in urban areas. Alberta has a universal publicly funded health care system that guarantees access to medically necessary hospital and medical services for all residents of the province. Virtually all (>99%) Alberta residents are registered with the system (28).

2.2.2 Data sources

Data for this study were gathered from three sources: the Alberta Ministry of Health and Wellness, the Alberta Trauma Registry, and the Office of the Chief Medical Examiner. The inclusion criteria for the study were: 1) spinal cord injuries or cauda equina injuries of traumatic origin, sustained between April 1, 1997 and March 31, 2000, and 2) Alberta residency at the time of injury.

Spinal cord injury (SCI) was defined as the occurrence of an acute traumatic lesion of neural elements in the spinal canal (spinal cord and cauda equina) resulting in resolving or permanent neurological deficit (29). For the purposes of this paper, 'SCI' refers to spinal cord injuries and cauda equina injuries. Cases from the Alberta Health and Wellness databases and the Alberta Trauma Registry were identified by the following *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) (30) diagnostic codes: 806.x (fracture of the vertebral column with SCI) or 952.x (SCI without evidence of spinal bone injury). The use of these two ICD-9-CM codes was based on the "Uniform Data Systems Cases Definition" recommended by the U.S. Centers for Disease Control and Prevention (29). This definition has been used extensively in trauma registries and surveillance systems to identify SCI (14, 15, 19, 26, 31). For the Medical Examiner's files, the operational definition was evidence of spinal cord injuries or cauda equina injuries in the autopsy report or death certificate (see below).

Alberta Health and Wellness databases: Alberta Health and Wellness maintains computerized records of all hospital and medical services in Alberta. Every Albertan has a unique personal health number, which is used to link records among different data sources within the Ministry. Demographic information is maintained in the Alberta Health Care Insurance Stakeholder Registry (28). Records of hospitalizations are collected in the Canadian Institute for Health Information Hospital Inpatient database (28). Separation abstracts are completed for each admission by trained medical records nosologists and contain admission and discharge dates, up to 16 ICD-9-CM diagnostic codes, and up to 10 ICD-9-CM procedure codes. A search of the Inpatient database identified Albertans who were hospitalized for SCI during the study period. Cases were included if they had an external cause of injury code (E code) consistent with traumatic SCI, and were admitted for at least one day to a trauma centre in Alberta. Patients were excluded if they had a subsequent diagnosis of a "conversion" disorder (ICD-9-CM code 300.11).

In Alberta, there are four regional trauma centres to which all severely injured patients are routinely transferred. It was assumed that all patients with a suspected SCI would be transferred to a trauma centre for confirmation of diagnosis and treatment. To examine the validity of ICD-9-CM diagnostic codes, a medical record review was conducted of a random sample of patients admitted to a large health region in Alberta. Two trauma centres are located within the health region. Searches were conducted of the inpatient and the emergency department (ED) databases for the period of April 1, 1998 to March 31, 1999. The first search identified patients coded with ICD-9-CM codes 806.x or 952.x (SCI codes). The second search identified patients coded with 805.x (fracture of the vertebral column without mention of spinal cord injury), 839.0 – 839.59 (dislocation of vertebra), or 953.x (injury to nerve roots and spinal plexus) (non-SCI codes). To avoid double counting patients who came through the ED prior to hospital admission, the search of the ED database was restricted to patients who died in the ED or who were discharged home without being admitted as an inpatient. Of the 860 patients identified by the searches, 100 had SCI codes and 760 had non-SCI codes. For the SCI codes, a random sample of 30 (30.0%) patients was selected. For the non-SCI codes, a random sample of 20 (5.1%) ED patients and 20 (5.5%) inpatients was selected. A total of 70 charts were reviewed to confirm the documentation of a newly diagnosed traumatic spinal cord injury or cauda equina injury, as determined by the presence of neurological damage or absence of motor and/or sensory function.

A separate chart review examined the medical records of all short-stay SCI patients (between 1 and 7 days) who were discharged home from a trauma centre between April 1, 1998 to March 31, 1999 (n=13). This was done to determine whether they represented valid SCI cases.

In addition to the Inpatient database, the Ambulatory Care Classification System database (28) was searched to identify individuals who were seen in the ED with a diagnosis of SCI, but who died prior to admission as an inpatient. The Ambulatory Care database is maintained by Alberta Health and Wellness and provides information about each patient encounter in all emergency departments in the province. For each visit, separation abstracts are completed by trained medical records nosologists and contain admission and discharge dates, up to 10 ICD-9-CM diagnostic codes, and up to 10 ICD-9-CM procedure codes.

Alberta Trauma Registry: The Alberta Trauma Registry collects detailed information on demographics, severity of injury, etiology, and contributing factors for all severely injured patients who were seen at a trauma centre in Alberta. Patients are included if they have an Injury Severity Score (ISS) of 12 or greater (32). The ISS is an anatomical scoring system that provides an overall score for patients with single or multiple injuries. The ISS score ranges from 1 to 75 with a higher score indicating increased severity. By definition, a patient with a true spinal cord injury will have a score of 12 or greater and, therefore, will be included in this registry. The registry was searched using the ICD-9-CM codes 806.x and 952.x to identify individuals who were admitted with SCI during the study period.

Office of the Chief Medical Examiner: The Medical Examiner investigates all sudden and unexplained deaths in Alberta. For all cases, an external examination is performed and, if warranted, an autopsy is conducted. Records include the identity of the person, date, time and place of death, and the cause and manner of death. Because the Office of the Medical Examiner updated its database in 1999, two databases were searched: pre-March 1999 and post-March 1999. Both databases are unique and the classification system used is different from those of the Alberta Health and Wellness and Alberta Trauma Registry databases described earlier. The search criteria for the pre-March database were accidental deaths, suicides, and undetermined deaths. For the post-March database, a keyword search was conducted of the 'Medical Cause of Death' section of the death certificate. In consultation with the Office of the Medical Examiner, the keywords used in the search were 'cervical', 'spine', 'spinal', or 'neck'. It was determined that keywords such as 'lumbar' or 'thoracic' were unlikely to appear in the cause of death section, but instead would be noted in the autopsy or external examination report. As well, a search was conducted to identify cases where the cause of death was multiple blunt trauma and where an autopsy had been conducted. SCI was confirmed if there was an autopsy or external examination report with specific mention of damage to the spinal cord, if the immediate cause of death on the death certificate was a fractured cervical spine, or if paralysis was noted in the emergency medical services, ED or hospital record.

Duplicate cases: To eliminate duplicate cases among the three data sources, probabilistic matching was performed. Cases were matched on sex, age or date of birth, date of admission or date of injury, and location of injury. All duplicate matches were assessed and removed from the database prior to analysis.

2.2.3 Ethics

This study was approved by the Health Research Ethics Board (B: Health Research), at the University of Alberta, Edmonton, Canada. To maintain the confidentiality of patients, all personal identifiers were removed prior to the release of data from the Alberta Ministry of Health and Wellness and the Alberta Trauma Registry.

2.2.4 Analyses

Population denominators from the Alberta Health Care Insurance Stakeholder Registry were used to construct annual age-sex specific rates of injury. The mid-year population census for 1998 was used for aggregated data. Place of residence (rural or urban) was determined using the postal code reported for each individual in the

Stakeholder Registry. Rural residents were identified by the presence of a zero in the second position of their postal code (33). This approach has been widely used in the analysis of data within this province. Statistical analyses included Student's *t* test and chi-square testing, where appropriate (alpha level was set at 0.05).

2.3 Results

2.3.1 Case ascertainment

Validity of inclusion criteria: Based on the chart review, 94% of inpatients with an ICD-9-CM code for SCI had a confirmed SCI (positive predictive value = 94.4%) (Appendix B). All patients with a confirmed SCI were admitted as inpatients to a trauma centre (sensitivity = 100%). Ninety-two per cent of short-stay patients demonstrated neurological symptoms or radiological evidence of injury to the spinal cord (Appendix C). These results confirmed the validity of the inclusion criteria.

From all data sources for the three-year study period, a total of 450 individuals were identified as having sustained a SCI.

Alberta Health and Wellness databases: From the Inpatient database, 562 cases were identified. Of these, 210 (37.4%) cases did not meet the criteria for inclusion: 127 (22.6%) were coded as medical/surgical complications, 62 (11.0%) were not admitted to a trauma centre, 11 (2.0%) sustained their injury prior to April 1, 1997, 7 (1.2%) were non-traumatic injuries, and 3 (0.5%) were eventually diagnosed with a "conversion" disorder. A total of 352 (62.6%) cases were identified from the Inpatient database. An additional 14 patients were identified through the Ambulatory Care database. Of these, three patients were dead on arrival (DOA) and 11 died in the ED before they could be admitted. Overall, a total of 366 eligible patients were identified from the Alberta Health and Wellness databases (Figure 2.1).

Alberta Trauma Registry: From the Alberta Trauma Registry, a total of 225 cases were identified. Of these, 201 (89.3%) were also located in the Alberta Health and Wellness databases (Figure 2.1).

Office of the Medical Examiner. A total of 1053 records were examined (Appendix D). Of these, 69 files identified a SCI. Fifty-five (79.9%) deaths occurred at the scene of injury, 5 (7.9%) patients were DOA or died in the ED, and 9 (13.0%) died during hospitalization. Of the 69 cases, 60 (87.0%) were located only in the Medical Examiner's files (Figure 2.1).

Figure 2.1 shows where the 450 cases were located and the overlap among the three sources. From the Alberta Health and Wellness data sources, 162 cases were not included in the Alberta Trauma Registry. Among these were individuals who died in the ED before transfer to a trauma centre (n=14). It is assumed that the remainder had ISS scores of less than 12 and experienced resolving neurological deficits. While it was anticipated that all cases identified in the Trauma Registry would appear in the Alberta Health and Wellness databases, in fact, 24 (10.7%) of the trauma registry cases were not located. Of these, 11 cases sustained their SCI toward the end of the study period and were not discharged from hospital until after March 31, 2000. Therefore, they would not have been included in the Alberta Health and Wellness data sources at the time that this study was initiated. It is not clear why the remaining 13 cases were not captured by the search of the Alberta Health and Wellness databases. Because the Medical Examiner collects information on individuals who die at the scene of injury and receive no hospital care, there was little overlap between their records and the other two sources.

2.3.2 Year of injury

Table 2.1 shows the demographics of the study cohort. There were no statistically significant differences for sex, age, and level of injury among the three years. For etiology, there was a statistically significant difference between Years 1 and 2 and Year 3. In Year 3, there were significantly fewer motor vehicle-related injuries and more fall-related injuries. However, for all years, motor vehicle collisions (MVC) were the leading cause of injury and falls were the second leading cause. All further analysis in this paper will aggregate data for the three years.

2.3.3 Age and sex

Of the 450 cases, 322 (71.6%) were male (Table 2.1). The median age for the total sample was 35.0 years (interquartile range (IQR) 22.0 to 48.25 years). The median age for males was 36.0 years (IQR 23.0 to 47.0 years) and for females, the median age was 33.0 years (IQR 20.0 to 54.0 years).

Seventy-one (15.8%) individuals died before they could be admitted to hospital. Of these, 45 (63.4%) were male. The median age was 27.0 years (IQR 18.0 to 45.0

years). Of the 379 people who survived to hospitalization, 277 (73.1%) were male. The median age of the hospitalized group was 36.0 years (IQR 24.0 to 49.0 years).

2.3.4 Incidence rates

The mean incidence rate was 52.5/1,000,000 population per year (95% confidence interval (CI): 47.7, 57.4) (Table 2.1). The mean annual incidence rate for males was 75.4/1,000,000 population and for females was 29.8/1,000,000. When only those who survived to hospitalization are included, the mean incidence rate was 44.3/1,000,000 population/year (95% CI: 39.8, 48.7). For males, the incidence rate was 64.9/1,000,000 and for females, it was 23.8/1,000,000.

Figure 2.2 shows the annual age-sex specific incidence rates. For all age groups males had higher incidence than females. The peak incidence rate for males was in the 20 to 29 year age group (138.0/1,000,000), with a second peak for those older than 70 years (98.9/1,000,000). For females, the peak incidence occurred in the 15 to 19 year age group (65.3/1,000,000). The incidence rate for females steadily increased after age 60 peaking at 58.7/1,000,000 for those who were 70 years and older.

The mean incidence rate for urban residents was 32.0/1,000,000 population/year (95% CI: 27.9, 36.2). For those living in rural areas, the incidence rate was 72.6/1,000,000/year (95% CI: 60.5, 84.8).

2.3.5 Etiology

Motor vehicle collisions accounted for the greatest number of SCIs. A total of 254 (56.4%) individuals were involved in a collision with a motorized vehicle, including drivers, passengers, pedestrians and bicyclists (Table 2.2). Falls were the second most common cause of injury with 86 (19.1%) people affected. Falls from an elevated level, such as stairs, roofs or ladders, occurred most often (64/86; 74.4%). Falls on the same level (slipping or tripping) were reported in 11 (12.8%) cases. The third most common cause of injury was sports and recreational activities, involving 51 (11.3%) individuals. Diving (9/51; 17.6%), bicycle crashes without motor vehicle involvement (7/51; 13.7%), and being thrown from an animal (6/51; 11.8%) were the leading sports-related causes.

For MVC-related injuries, the highest incidence for males occurred between ages 20 and 29 years, with an annual rate of 88.8/1,000,000 (Figure 2.3). There was a second, smaller peak for those aged 70 years and older (45.3/1,000,000). For females, MVC-related injury was highest in the 15 to 19 age group (58.8/1,000,000) (Figure 2.4). The incidence of motor vehicle injuries for males was higher than for females for all age groups.

For males, the incidence of fall-related injuries steadily increased beginning with the 40 to 49 year age group and leveled off after the age of 60 (Figure 2.3). For females, fall-related injuries increased sharply after the age of 60 years and surpassed that of males among those older than 70 years (Figure 2.4). Of the 29 individuals who had a fall on the same level or from stairs, 18 (62.1%) were 60 years and older.

2.3.6 Level and severity of injury

Two hundred and seventy-seven (61.5%) individuals sustained an injury at the cervical level, while 155 (34.4%) sustained an injury at the thoracic, lumbar or sacral level (Table 2.3). The neurological lesion was complete in 82 (18.2%) cases (Table 2.3). Persons who died prior to hospitalization were more likely to have been injured at the cervical level than those who were hospitalized (87.3% vs. 56.7%; $p < 0.001$).

The median length of stay in acute care institutions was 15.0 days (IQR 7.0 to 26.0 days). In addition to the 71 people who died before being admitted to hospital, 29 people died during their initial hospitalization. The case fatality rate for all SCIs was 22.2%. For those who survived to hospital admission, it was 7.7%. Of the 100 deaths, 32 (32.0%) individuals died from isolated SCI at the cervical level. Of these, nine were injured at C 1–4, three were injured at C 5–7, and 20 were injured at an unspecified cervical level. Thirty-one (96.9%) persons who died from isolated SCI died at the scene of injury or were DOA. Sixty-eight (68.0%) persons who died sustained other injuries in addition to their SCI, including head injuries, hemo- or pneumothorax, and multi-system trauma.

2.4 Discussion

This study examined the incidence and pattern of traumatic SCI over a three-year period in a Canadian province with centralized, uniformly coded databases. Case ascertainment was comprehensive and included an examination of all hospital and ED separations in the province, data from a trauma registry, and death certificate reports (chart and autopsy) from a coroner's office. The results of this study suggest that such a strategy is required in order to accurately identify all cases of SCI.

Overall, the 450 cases resulted in a mean annual incidence rate of 52.5 per million population. For those who survived to hospital admission, the incidence rate was 44.3 per million, which is higher than the estimate used by the Canadian Paraplegic Association (11), but corresponds closely with the rates reported by a recent population-based study from the province of Ontario, Canada (14). This close agreement with the Ontario results supports the accuracy of the rates presented in this study. In other population-based studies, the incident rates ranged from 43 to 93 per million population when pre-hospital deaths are included (12, 13, 16, 25, 26). When only those who survived to hospitalization are included, the incidence rates ranged from 15 to 83 per million (10, 12, 13, 15, 16, 26, 31, 34, 35).

The SCI case fatality rate in Alberta for individuals who were admitted to hospital was 7.7%, which is similar to the rate of 7% reported by Tator et al. (22). Population-based studies from the United States have reported case fatality rates ranging from 3.6% to 21.5% when restricted to persons who survived to hospital admission (7, 12, 13, 15, 16, 26, 36). When persons who died prior to hospitalization are included, the case fatality rate for Alberta was 22.2% which is within the range of 18.4% to 78.6% reported in other studies (12, 13, 16, 26).

The current study reaffirms that males are at greater risk for SCI than females, with a male to female ratio of 2.5:1 (7, 12, 13, 15, 19, 22, 24, 26, 34, 37). For every age group, the incidence rates for males were higher than for females.

Consistent with other research, the highest incidence occurred among individuals between the ages of 15 and 29 years (7, 12, 15, 26, 34). A second, smaller peak in incidence occurred in persons over the age of 70 years. A similar increase in injury among older individuals has also been observed (12, 13, 37). Pickett et al. reported that in Ontario the highest incidence rates were experienced by those 70 years and older (14). In the current study, the rate for females older than 70 years approached that of the group with the highest incidence (15 – 19 years), but did not surpass it.

Motor vehicle collisions were the main cause of SCI for individuals under the age of 60 years. Those older than 60 years were at greater risk for sustaining a fall-related injury. Falls surpassed MVC as the primary cause of injury for females older than 60 years and for males older than 70 years. Similar patterns have been previously reported (12-15, 34).

Overexertion and strenuous movement (E927) was identified as a cause of injury for two individuals in this study (Table 2.2). From the Alberta Health and Wellness Inpatient database it is not possible to determine the exact circumstances of injury; however, Mikawa et al. reported on a 52-year old man with tetraplegia caused by doing push-ups (38). Other studies have also noted overexertion and strenuous movement as a cause of SCI, however no details as to circumstances were provided (14, 34).

In the present study, the incidence of SCI among rural residents was twice that of urban dwellers. This difference has not been reported in previous research on SCI. However, studies have reported higher rates of injury in general among people who live in rural areas (39-41).

The data from this study suggest that the strongest efforts at preventing SCI should focus on males, individuals between the ages of 15 and 29 years, rural residents, and MVC. Strategies to prevent SCI in older adults should be directed at the prevention of falls.

This research has also highlighted the importance of using multiple sources of data to obtain a complete picture of SCI. The three data sources enabled more complete case ascertainment. Included were pre-hospital fatalities, persons with resolving neurological deficits, and those with injuries resulting in permanent neurological impairment. The Alberta Health and Wellness databases identified the greatest number of cases, capturing 81.3% of the total eligible cases and 93.8% of hospitalized cases. The Alberta Trauma Registry identified 50% of the total cases and 57.8% of hospitalized cases. Use of the Trauma Registry data alone would not only underestimate the incidence of SCI, but also misrepresent the nature and extent of injury. Excluded from the Trauma Registry data are individuals who may have experienced resolving neurological deficits. Research has shown that more than 80% of patients who were minimally disabled at hospital discharge (functional motor recovery or full recovery) reported some problem or unmet need up to four years following their injury (42).

In the original search of the Alberta Health and Wellness Inpatient database, 127 individuals sustained a SCI as a result of medical/surgical complications. These patients were excluded from the current study, which was an examination of traumatic SCI. The patients, who underwent a spine-related surgical procedure, were assigned ICD-9-CM codes 998.2 (accidental puncture or laceration during a procedure) and E870.x – E879.x (misadventures to patients during surgical and medical care). No other E code was assigned to the patient visit. It is beyond the scope of the present paper to examine what these cases represent but we note it as a topic that may warrant further investigation.

Potential limitations of this study need to be discussed. First, without access to all medical charts for patients who were identified solely through the Alberta Health and Wellness databases, it is impossible to state unequivocally that SCI was a true diagnosis. While administrative data have been found to have high concordance with chart reviews and patient interviews (23, 43, 44), there is still the possibility of misclassification of cases due to coding errors or incomplete data entry. We did perform chart reviews (n=83) to evaluate our selection criteria for inpatient hospitalizations. Overall, these reviews confirmed the validity of the selection criteria and coding.

Second, the exclusion of patients admitted to a non-trauma centre without a subsequent transfer to a trauma centre (62 cases) may have missed individuals with rapidly resolving neurological deficits and would result in an underestimate of cases. We felt this was necessary, since it is common practice for all true SCIs to be transferred to major trauma centres where neurosurgical assessment and consultation can be obtained. Third, ascertainment of pre-hospital deaths is likely incomplete. Many patients who died at the scene from multiple severe injuries, especially head trauma, may have had undetected SCIs and would not have been identified through the review of Medical Examiner's files (13, 26). It is impossible to estimate the number of cases that were undetected and this has not been attempted. Lastly, the data on level and extent of injury reflect discharge diagnoses and do not reflect neurological outcomes or functional recovery that may have occurred following discharge. Notwithstanding the above concerns, this study represents the most comprehensive population-based study on SCI in Canada.

2.5 Conclusion

This research has provided a current and accurate measure of the incidence and nature of SCI in a geographically defined region of Canada. Those at highest risk for injury are males, individuals in their late teens or 20s, and rural residents. The most common cause of injury is motor vehicle collision. For persons older than 60 years, falls become an increasing risk for SCI.

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Table 2.1. Demographics of spinal cord injury cases in Alberta, Canada, April 1, 1997 – March 31, 2000 (N=450)

	Year 1†	Year 2†	Year 3†	Total
Number of cases (%)	159 (35.3%)	151 (33.6%)	140 (31.1%)	450 (100%)
Incidence rate / million / year	57.0	52.9	47.9	52.5
95% confidence interval	48.1, 65.8	44.5, 61.3	39.9, 55.8	47.7, 57.4
*Sex (Male (%))**	115 (72.3%)	110 (72.8%)	97 (69.3%)	322 (71.6%)
Age				
Median	32.0 yrs.	34.0 yrs.	37.5 yrs.	35.0 yrs.
Interquartile range	20–45 yrs.	24–47 yrs.	24–51.75 yrs.	22–48.25 yrs.
*Level of injury (No. (%))**				
Cervical	103 (64.8%)	87 (57.6%)	87 (62.1%)	277 (61.5%)
Thoracic	23 (14.5%)	32 (21.2%)	23 (16.4%)	78 (17.3%)
Lumbar/Sacral/Cauda Equina	25 (15.7%)	24 (15.9%)	28 (20.0%)	77 (17.1%)
Unspecified	8 (5.0%)	8 (5.3%)	2 (1.4%)	18 (4.0%)
*Etiology (No. (%))***				
Motor vehicle collisions	95 (59.7%)	90 (59.6%)	69 (49.3%)	254 (56.4%)
Falls	25 (15.7%)	22 (14.6%)	39 (27.9%)	86 (19.1%)
Sports & recreation	15 (9.4%)	19 (12.6%)	17 (12.1%)	51 (11.3%)
Other	24 (15.1%)	20 (13.2%)	15 (10.7%)	59 (13.1%)

* $p \geq 0.05$; ** $p < 0.05$.

†Year 1 = April 1, 1997 – March 31, 1998; Year 2 = April 1, 1998 – March 31, 1999; Year 3 = April 1, 1999 – March 31, 2000.

Table 2.2. Etiology of spinal cord injury in Alberta, Canada, April 1, 1997 – March 31, 2000 (N=450)

Cause of injury	Male	Female	Total
Motor vehicle collisions (N=254; 56.4%)			
Traffic related	140 (43.5%)	69 (53.9%)	209 (46.4%)
Snowmobile/ATV	23 (7.1%)	2 (1.6%)	25 (5.6%)
Pedestrian	10 (3.1%)	7 (5.5%)	17 (3.8%)
Other motor vehicle collisions	3 (0.9%)		3 (0.7%)
Falls (N=86; 19.1%)			
Building	20 (6.2%)	1 (0.8%)	21 (4.7%)
Stairs	5 (1.6%)	13 (10.2%)	18 (4.0%)
One level to another	13 (4.0%)	3 (2.3%)	16 (3.6%)
Same level (slipping or tripping)	5 (1.6%)	6 (4.7%)	11 (2.4%)
Scaffold/ladder	7 (2.2%)	2 (1.6%)	9 (2.0%)
Unspecified	6 (1.9%)	5 (3.9%)	11 (2.4%)
Sports & recreation (N=51; 11.3%)			
Diving	8 (2.5%)	1 (0.8%)	9 (2.0%)
Bicycling	7 (2.2%)		7 (1.6%)
Thrown from animal	4 (1.9%)	2 (1.6%)	6 (1.3%)
Skiing/Snowboarding	3 (0.9%)	3 (2.3%)	6 (1.3%)
Other	7 (2.2%)	2 (1.6%)	9 (2.0%)
Unspecified	13 (4.0%)	1 (0.8%)	14 (3.1%)
Struck by object/person (N=24; 5.3%)	20 (6.2%)	4 (3.1%)	24 (5.3%)
Intentional (N=20; 4.4%)			
Assault	10 (3.1%)	1 (0.8%)	11 (2.4%)
Self-inflicted	4 (1.2%)	5 (3.9%)	9 (2.0%)
Other/Unspecified (N=15; 3.3%)			
Other transportation	7 (2.2%)	1 (0.8%)	8 (1.8%)
Firearms (unintentional)	2 (0.6%)	1 (0.8%)	3 (0.7%)
Overexertion/strenuous movement	2 (0.6%)		2 (0.4%)
Unspecified	2 (0.6%)		2 (0.4%)
Total	322	128	450

Table 2.3. Distribution of spinal cord injury by level and severity in Alberta, Canada, April 1, 1997 – March 31, 2000 (N=450)

	Level of lesion	Complete	Incomplete	Unspecified	Total
Admitted to hospital (N=379)					
	C1 – C4	9	30	38	77
	C5 – C7	26	73	39	138
	Cervical unspecified				
	Thoracic	31	21	23	75
	Lumbar		69		69
	Sacral, Cauda Equina		6		6
	Unspecified			14	14
Died at scene, DOA or died in ED (N=71)					
	C1 – C4	8	1	14	23
	C5 – C7	1	1	2	4
	Cervical unspecified	3		32	35
	Thoracic	2		1	3
	Lumbar	2			2
	Sacral, Cauda Equina				
	Unspecified			4	4
Total		82	201	167	450

Figure 2.1. Case ascertainment from 3 data sources for spinal cord injury in Alberta, Canada, April 1, 1997 – March 31, 2000 (n = 450).

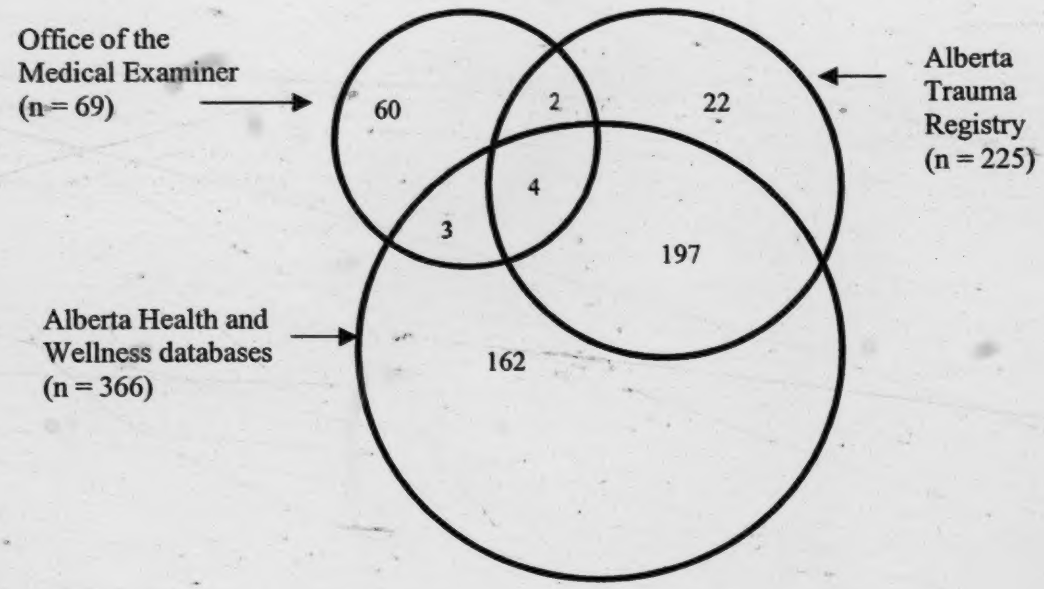

Office of the Medical Examiner (n = 69)
Alberta Trauma Registry (n = 225)
Alberta Health and Wellness databases (n = 366)
60
2
22
4
3
197
162

Figure 2.2. Annual age-sex specific incidence rates for spinal cord injury in Alberta, Canada (n = 450)

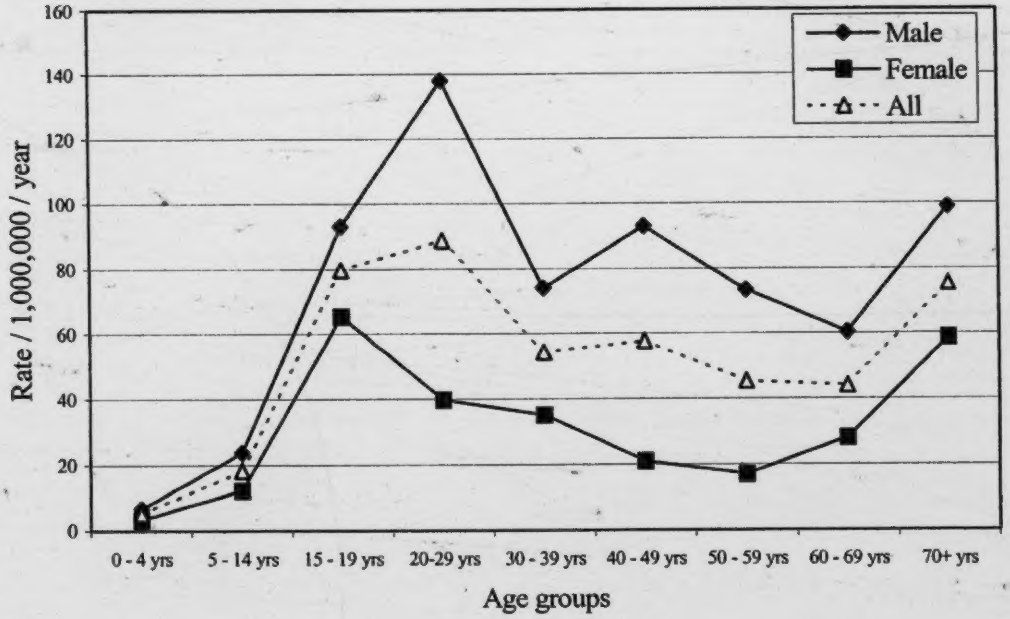


Figure 2.3. Male age-specific annual incidence rates for etiology of spinal cord injury in Alberta, Canada (n = 322).

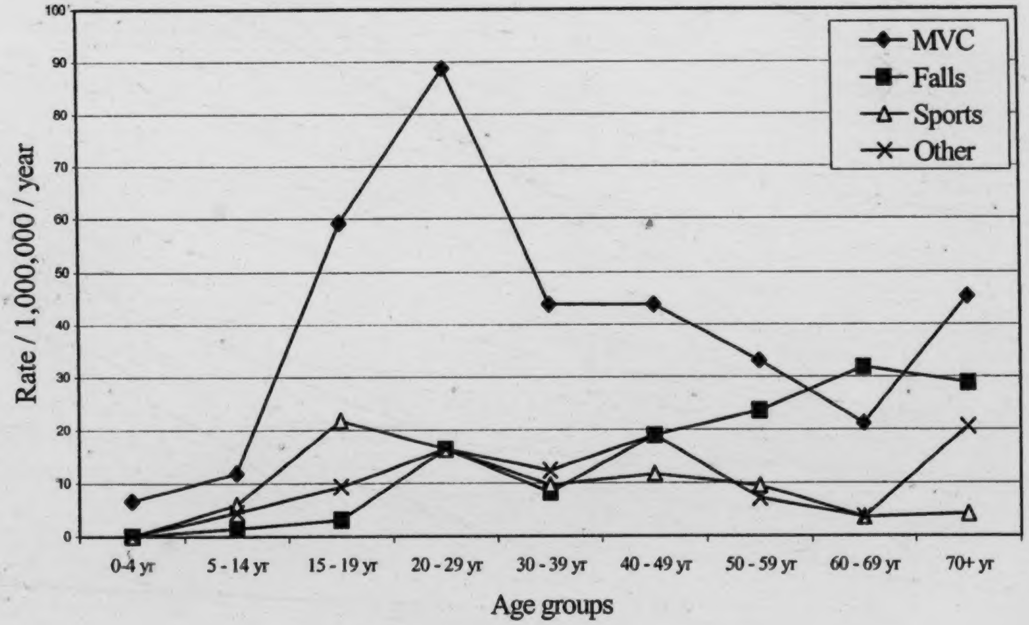
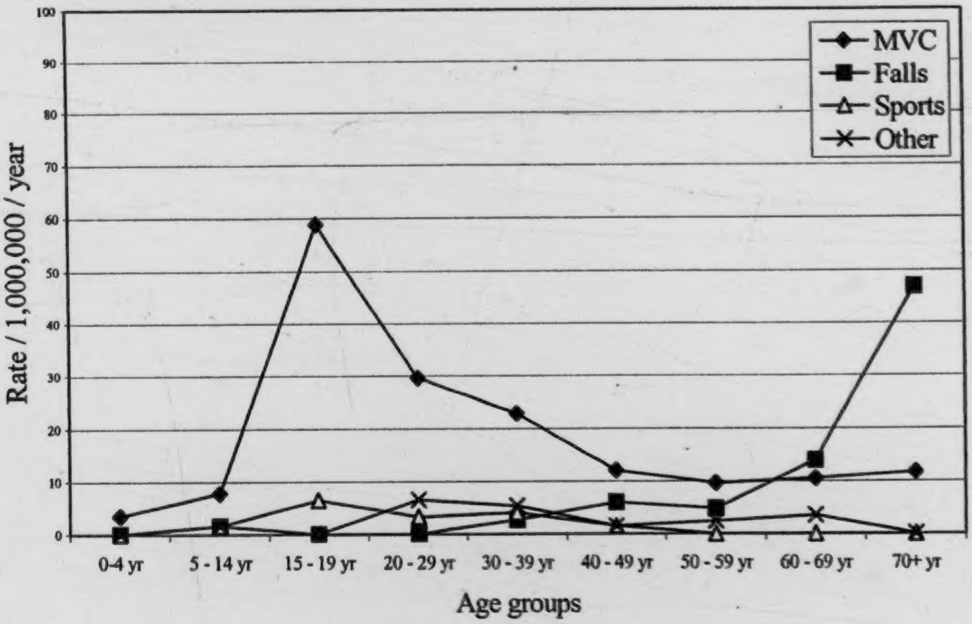


Figure 2.4. Female age-specific incidence rates for etiology of spinal cord injury in Alberta, Canada (n = 128)



Chapter 3

The Utilization of Health Services Following Traumatic Spinal Cord Injury: A Six Year Follow-up Study[4]

3.1 Introduction

In the months and years following acute trauma, persons with spinal cord injury (SCI) are at risk for a number of secondary health conditions, which can result in frequent contact with physicians and other health providers and hospitalization (1). In a cross-sectional study of Model SCI System (United States) patients, researchers found that 95.6% of patients had at least one medical complication at the time of their routine annual check-up (2). Between 28% and 35% of patients (depending on level of injury) had a urinary tract infection and 22.4% had decubitus ulcers. In a population-based survey of persons with SCI in Quebec, Canada, researchers found that 56% had experienced a urinary tract infection in the previous year, and 28% reported a decubitus ulcer (3). Respiratory, cardiovascular and psychosocial issues have also been shown to be prevalent in studies of post-acute SCI patients (3-7). Persons with SCI are two times more likely to be re-hospitalized than the general population of the United States (4). The proportion of people with SCI who are re-hospitalized in a given year has been reported between 27% and 57% (1, 4, 8-11). The highest rates of re-admission to hospital occur in the first five years following injury (10, 11). In a study of hospitalizations in the first year post-injury, Davidoff et al. found the leading reasons for admission were urinary tract infections (17.0%) and deep venous thrombosis (12.8%) (8). Beyond the first post-injury year, Meyers et al. found that respiratory complications (19%), urinary tract infections (14%), and dermatological conditions (7%) were the primary reasons for hospital admissions (9).

Ongoing complications and hospital admissions are costly (1, 12-14). They disrupt work, education and interpersonal relationships, and may negatively impact quality of life (15). In order to assist health care providers develop effective programs for persons with SCI, it is important to have a clear understanding of the nature and extent of health service utilization. While previous research has provided some information in this regard, many studies suffer from methodological limitations. Most studies are cross-sectional and report on the experiences of individuals who have been injured for varied lengths of time and are therefore at different states of risk (1, 3, 6, 10). Some studies are restricted to a single health care centre or service provider, which may limit their generalizability (10, 11). Others have relied on interviews and patient surveys, which may be affected by recall bias (1, 3, 4).

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[4] A version of this chapter has been submitted for publication: Dryden et al 2003. Spinal Cord.

The present study addresses some of these limitations using a population-based cohort design to follow persons who sustained a traumatic SCI in Alberta, Canada. Administrative data from centralized databases were compiled to provide a complete picture of health care use following SCI, including hospital admissions, physician contacts, long-term care, and home care services. The primary objectives of this study were: 1) To describe health care utilization by persons with SCI from date of injury to 6-years post-injury; 2) To describe the incidence and pattern of secondary medical complications following injury; and 3) To compare the utilization of health services by persons with SCI with that of the general population.

3.2 Methods

3.2.1 Study location

Alberta is located in western Canada and occupies an area of approximately 661,000 square kilometers. In 1993 the population was estimated as 2.7 million, of which 75% lived in urban areas. Alberta has a universal publicly funded health care system that guarantees access to medically necessary hospital and medical services for all residents of the province. Virtually all (>99%) Alberta residents are registered with the system (16).

3.2.2 Definition of SCI

SCI was defined as the occurrence of an acute traumatic lesion of neural elements in the spinal canal (spinal cord and cauda equina) resulting in resolving or permanent neurological deficit. Cases were identified by the *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) diagnostic codes for SCI: 806.x (fracture of the vertebral column with SCI) or 952.x (SCI without evidence of spinal bone injury). The use of these two ICD-9-CM codes was based on the "Uniform Data Systems Cases Definition" recommended by the U.S. Centers for Disease Control and Prevention (17). This definition has been used extensively in trauma registries and surveillance systems to identify SCI (18-20).

3.2.3 Data sources

Data for this study were gathered from the Alberta Ministry of Health and Wellness (16). The Ministry maintains computerized records of all hospital and medical services in Alberta. Every Albertan has a unique personal health number, which is used to link records among different data sources within the Ministry. The reliability and utility of administrative health care data have been established (21-24).

Records from five databases were used to compile information on individual encounters with the Alberta health care system during the 6-year follow-up period. The data sources were:

Alberta Health Care Insurance Stakeholder Registry (Stakeholder Registry): This database contains demographic information about Albertans registered with the health care system.

Canadian Institute for Health Information (CIHI) Hospital Inpatient database (Inpatient database): Records of all hospitalizations in Alberta are collected in the Inpatient database. Separation abstracts are completed for each admission by trained medical records nosologists and contain admission and discharge dates, up to 16 ICD-9-CM diagnostic codes, and up to 10 ICD-9-CM procedure codes.

Alberta Health Insurance Plan Payment Data (Physician claims database): This is a database of fee-for-service claims submitted by physicians and other health service providers (e.g., optometrists and chiropractors) in Alberta for the provision of medically required services. For the purposes of this research, only physician claims are reported and include medical, surgical, obstetric, anesthesia and diagnostic services. For claims made in 1992 and 1993, one 3-digit ICD-9-CM diagnostic code was assigned to each contact. Since 1994, up to three 4-digit ICD-9-CM codes were assigned for each encounter.

Long Term Care Resident Classification (Long-term care): Data are collected for all residents in long-term care institutions during the annual assessment period. Individuals are included if they were classified during the previous year or are resident at the time of assessment. Admission to a long-term care facility and nursing care intensity were used as measures of long-term care.

Home Care Information System (Home care): The database provides information on clients receiving services provided under the home care program including nursing care, meal services, and other support for activities of daily living. Total hours of service and service duration were used as measures of home care utilization.

3.2.4 Inclusion criteria and case identification

A search of the Inpatient database identified Albertans who were hospitalized for SCI during the study period. The date of the index hospitalization was considered the date of the SCI. The inclusion criteria for the study were: 1) admission to a hospital in Alberta, between April 1, 1992 and March 31, 1994, with an ICD-9-CM code for SCI, 2) transfer to an acute care centre in Edmonton or Calgary, the two major cities in the province, 3) an external cause of injury code (E code) consistent with traumatic SCI, and 4) Alberta residency at the time of injury. In Alberta, all severely injured patients are routinely transferred from smaller, rural hospitals to an acute care centre. Therefore we assumed that all patients with a suspected SCI would be transferred to Edmonton or Calgary for confirmation of diagnosis and treatment. Patients were excluded if they had a subsequent diagnosis of a "conversion" disorder (ICD-9-CM code 300.11) or if there was a record of a hospital or physician claim for SCI within 30 days prior to the index visit.

3.2.5 Control group

For comparison with the general population, each SCI case was matched to five controls randomly selected from the Stakeholder Registry. Controls were matched with SCI cases for age, sex and region of residence (to control for distance and access to health services). Individuals were not eligible to be controls if they sustained a SCI at any time during the follow-up period or if there was evidence of a prior SCI (ICD-9-CM codes 952.x, 806.x or 907.2 [late effect of SCI]).

3.2.6 Follow-up period

Data on health care utilization were collected from date of injury for each SCI case to six years post-injury. For each individual in the control group, data were collected from the date of injury of their respective cases to six years after the date of injury.

Deaths and losses to follow-up were confirmed in the Stakeholder Registry. Persons who were lost to follow-up were presumed to have moved from the province.

The initial hospitalization period refers to the episode of care in the hospital system from date of SCI to the first definitive discharge to the community or to a long-term care facility. It includes admissions to rural hospitals prior to transfer to an acute care hospital in Edmonton or Calgary, acute care hospitalization, and inpatient rehabilitation. For patients who received acute and rehabilitation care in the same hospital (~40%), it was not possible to separate the acute care and inpatient rehabilitation phases.

For subsequent hospital admissions (after initial hospitalization for SCI cases), the reason for admission was determined by the principal diagnosis for each hospitalization. For physician visits, the reason for the contact was determined by the first diagnostic code for each physician claim. Reasons for admissions or contacts were grouped into diagnostic categories following the ICD-9-CM (Appendix E).

A number of secondary complications were selected for examination: urinary tract infection, decubitus ulcer, pneumonia, septicemia, deep vein thrombosis, and pulmonary embolism. The presence of a complication was determined by an ICD-9-CM code for the condition in any diagnostic field in the Inpatient database and the Physician claims database (Appendix F). This study also examined depression following SCI. The working definition of depression was an ICD-9-CM code for depressive disorders (311), affective disorders (296.x), adjustment reaction (309.x), or neurotic depression (300.4). A person was determined to have depression if there was at least one diagnosis in the Inpatient database or if there were two or more physician contacts for depression over the follow-up period (22, 24).

3.2.7 Ethics

This study was approved by the Health Research Ethics Board (B: Health Research) at the University of Alberta, Edmonton, Canada. To maintain the confidentiality of patients, all personal identifiers were removed prior to the release of data from the Alberta Ministry of Health and Wellness.

3.2.8 Analyses

Descriptive statistics for demographic and injury characteristics are presented using frequencies and percentages for categorical data, and medians and interquartile ranges (IQR) for continuous variables. Annual age-sex specific rates of injury and 95% confidence intervals (95% CI) were constructed using the registrant count at June 30, 1993 from the Stakeholder Registry as population denominators. Place of residence (rural or urban) was determined using the postal code reported for each individual in the Stakeholder Registry. Rural residents were identified by the presence of a zero in the second position of their postal code (25). Differences between groups were tested using the Mann-Whitney U test and chi-square, where appropriate (alpha was set at 0.05).

Rates for hospital admissions and physician contacts are reported as admissions or contacts per person-year or 100 person-years. Poisson regression with generalized estimating equations was used to compare number of hospitalizations and physician contacts between the SCI group and the control group (26, 27). Results are presented as rate ratios (RR) with 95% CI.

3.4 Results

3.4.1 Case ascertainment

From the Inpatient database, a total of 233 patients met the inclusion criteria for traumatic SCI and were included in the follow-up study. A total of 1165 matched controls were selected from the general population. The mean incidence rate was 43.5 per million population per year (95% CI: 37.9, 49.1). The mean annual incident rate for males was 65.9 per million population (95% CI: 56.1, 75.6) and for females was 21.3 per million (95% CI: 15.7, 26.8). For rural residents, the incidence rate was 70.7 per million per year compared with 31.4 per million per year for those living in urban areas.

3.4.2 Demographics and injury characteristics

Of the 233 individuals who sustained a SCI, 176 (75.5%) were male (Table 3.1). The median age for the total sample was 34.0 years (IQR 24.0 to 48.0). Ages ranged from 9 to 95 years. The median age differed between males (32.0 years; IQR 22.5 to 46.5) and females (41.0 years; IQR 29.0 to 69.0) (U=3585.5, p=0.001). Due to matching, the age and sex distribution of the control group was the same as the SCI group.

Motor vehicle collisions accounted for the greatest number of SCI (Table 3.1). A total of 116 (49.8%) individuals were involved in a collision with a motorized vehicle, including drivers, passengers, pedestrians and bicyclists. Falls were the second most common cause of injury with 61 (26.2%) people affected.

One hundred and seventeen (50.2%) individuals sustained an injury at the cervical level, while 98 (42.1%) sustained an injury at the thoracic, lumbar, sacral, or cauda equina level (Table 3.1). Forty-three (18.5%) of the injuries were classified as complete and 69 (30.0%) were incomplete. For 121 (51.9%) cases the extent of SCI was not specified (Table 3.1).

One hundred and forty-two (60.9%) individuals sustained another injury in addition to their SCI (Table 3.1). Overall, 51 (21.9%) people were diagnosed with a traumatic brain injury in addition to their SCI.

3.4.3 Deaths and losses to follow-up

Twenty (8.6%) SCI patients died during their initial hospitalization (Table 3.1). The median time to death was 10.0 days (IQR 5.0 to 19.0) ranging from 2 to 134 days. During the 6-year follow-up period, a greater proportion of persons in the SCI group (16 {7.5%}) died than in the control group (45 {3.9%}) (χ^2=47.8, p<0.001). For both groups, the individuals who died were significantly older than those who were alive at the end of the follow-up period.

In addition to those who died during the follow-up period, 119 people were lost to follow-up. Among individuals with SCI, 20 (10.2%) were lost to follow-up compared with 99 (8.9%) people from the control group (χ^2=0.35, p=0.55). There were no statistically significant differences in age and sex between those lost to follow-up and those followed to the end of the study period in either the SCI or control group.

3.3.4 Discharge status

Following initial hospitalization, 10 (4.7%) people were discharged to a long-term care facility. The median age for this group was 69.0 years (IQR 38.0 to 78.0). During the follow-up period an additional eight people were admitted to a long-term care facility. From the control group, 20 (1.7%) people were admitted to a long-term care facility. The SCI group required a greater level of nursing care in long-term care with 73.3% receiving care at the two highest levels compared with 40.3% from the control group (χ^2=8.8, p=0.003).

3.3.5 Initial hospitalization

During initial hospitalization, including acute care and inpatient rehabilitation, the SCI group was hospitalized for a total of 14,200 days (Table 3.2). The median length of stay (LOS) was 26 days (IQR 6 to 98) and ranged from 1 to 450 days. For patients with a complete SCI, the median LOS was 140 days (IQR 88 to 171); for those with incomplete injuries, it was 51 days (IQR 16 to 93). Where extent of SCI was unspecified, the median LOS was 10 days (IQR 4 to 30). For 78 patients, it was possible to identify the acute care and inpatient rehabilitation phases of care. For the acute care phase the median LOS was 24 days (IQR 16 to 43), while for inpatient rehabilitation it was 72 days (IQR 46 to 106).

3.3.6 Re-hospitalizations

For patients who were discharged alive following initial hospitalization, 122 (57.3%) were re-hospitalized at least once during the follow-up period for a total of 365 admissions (Table 3.2). Over the 6-year follow-up, the median LOS was 4 days (IQR 2 to 9) per hospitalization and ranged from 1 to 277 days. The number of hospital admissions per person ranged from 1 to 27. Fifty-seven (46.7%) people were hospitalized once, 21 (17.2%) were hospitalized twice, 39 (32.0%) were admitted between three and nine times, and five (4.1%) were re-hospitalized on 10 or more occasions.

Following initial discharge, individuals with SCI had 2.6 (95% CI: 2.3, 3.0) more hospital visits than the control group (Figure 3.1). The SCI group was hospitalized for 3.03 days per person-year compared with 0.92 days per person-year for the control group. The median LOS for the control group was the same as the SCI group (4 days; IQR 2 to 8).

Figure 3.2 illustrates the distribution of hospital admissions by diagnostic category. For both the SCI and control groups, respiratory diseases, digestive system diseases and injuries were the most common principal diagnoses associated with hospital admissions. However, for every diagnostic category, the SCI group had more admissions and a greater proportion of people admitted compared with the control group.

3.3.7 Physician contacts

Over the 6-year follow-up period, the SCI group had 17,227 contacts with physicians, including outpatient visits and during hospitalization (Table 3.3). In the year of injury, the median number of contacts was 22 (IQR 12 to 37). In the subsequent five years, the median number of contacts declined from 8 (IQR 3 to 16) in the second post-injury year to 4 (IQR 0 to 10) in the sixth year (χ^2=5.0, p=0.03). For the control group, the median number of contacts per year was 3 (IQR 1 to 6). Over the 6-year follow-up period, there were more physician contacts by the SCI group than the control group (RR=2.7, 95% CI: 2.6, 2.71).

In the first post-injury year, the SCI group visited family physicians, physical medicine specialists and internists most frequently (Figure 3.3). In the subsequent five years, family physicians, internists, and psychiatrists were seen most often. Over the 6-year follow-up, the control group also visited family physicians, internists, and psychiatrists most often. The number of visits to specialists and the proportion of people seeing specialists were higher among persons with SCI.

Figure 3.4 shows number of physician contacts by diagnostic category. For the SCI group, visits to physicians in the first post-injury year appear to be related to the initial injury episode and associated neurological symptoms. In the subsequent five years, the main reasons for visits were ill-defined symptoms, injuries, disorders of the genitourinary system, and mental disorders. For the control group, the main reasons for physician visits were ill-defined symptoms, disorders of the respiratory system, musculoskeletal diseases, and mental disorders. For all diagnostic categories, the SCI group were seen more often than the control group.

3.3.8 Secondary complications

During initial hospitalization, 106 (45.5%) patients were treated for a urinary tract infection, decubitus ulcer, pneumonia or septicemia (Table 3.4). Of these, 32 (13.7%) individuals were treated for more than one of these complications. Most (93.2%) patients with complete injuries were treated for at least one complication, compared with 47.1% of those with incomplete injuries and 29.8% of those where the extent of SCI was not specified. After discharge from initial hospitalization, 94 (44.1%) people were treated for a urinary tract infection, decubitus ulcer, pneumonia or septicemia either during a subsequent hospitalization or by a physician (Table 3.4). Of these, 31 (33.3%) had more than one complication.

Over the 6-year follow-up, 111 (47.6%) people with SCI were treated for a urinary tract infection, either during initial hospitalization, a subsequent hospitalization, or by a physician (Figure 3.5). Seventy-nine (33.8%) people were treated for pneumonia, 46 (19.7%) for decubitus ulcer, and 36 (15.5%) for septicemia. For each complication, a higher proportion of individuals from the SCI group were treated for one of these conditions compared with the control group (Figure 3.5).

Eight (3.4%) people with SCI were treated for venous thromboembolism following their injury (Figure 3.5). Three people were treated during initial hospitalization and four were treated within the first year of injury. One individual was treated in the fifth year post-injury. Eleven (4.7%) people were treated for pulmonary embolism (Figure 3.5). Nine were treated during initial hospitalization and two were treated within the first year post-injury. Within the control group, three individuals (0.3%) were treated for venous thromboembolism and three (0.3%) for pulmonary embolism over the 6-year follow-up.

Over the entire follow-up period, 64 (27.5%) individuals with SCI were treated for depression (Figure 3.5). Twenty-six people were treated during initial hospitalization and an additional 38 were treated either during a subsequent hospitalization or as an outpatient. Among the control group, 10.8% were treated for depression. Persons with SCI were more likely to be treated by a psychiatrist and more likely to be re-hospitalized for a mental disorder than the control group (Figures 3.2 & 3.3).

3.3.9 Home care

Following discharge from initial hospitalization, 66 (31.0%) individuals with SCI received a total of 76,588 hours of home care services, or 65.0 hours per person-year. This compares with 73 persons from the control group who received 2.2 hours per person-year.

3.4 Discussion

This study examined the utilization of health services following traumatic SCI over a 6-year period in a Canadian province with universal health care and centralized health care databases. Utilization of health services was compared with that of a control group randomly selected from the general population of the province and matched on age, sex and region of residence. Information on utilization was comprehensive and included an examination of all hospitalizations, long-term care admissions, fee-for-service physician contacts, and home care services in the province.

Overall, 233 individuals with traumatic SCI were followed from their date of injury to six years post-injury. Many spent prolonged periods in hospital and often required re-admission. Following initial hospitalization, persons with SCI were hospitalized 2.6 more times than their matched controls. They also had 2.7 more contacts with physicians and required 30 times more hours of home care services. After the first year post-injury, the pattern of health care use in terms of diagnoses was similar to that of the control group. For both groups the primary reasons for hospitalization related to respiratory and digestive disorders, and family physicians and internists were the physicians most frequently contacted. However, the rates of utilization for each diagnostic category and physician specialty were higher for persons with SCI compared with their matched controls.

These results support previous generic research, which shows that persons with disabilities or chronic diseases use health services more than the general population (28, 29); however, limited research has specifically examined persons with SCI. In a Swedish study, Levi et al. compared the health profile of persons with chronic SCI with that of the general population (30). Data for their study were derived from the annual 'Level-of-Living' survey conducted by the Swedish Bureau of Statistics. They found that persons with SCI experienced significantly more health problems than the general population and reported a higher prevalence of medical symptoms, greater use of medications, more emergency department visits, and more hospital admissions. They also found a higher prevalence of dysfunctions related to SCI, such as bladder dysfunction and skin problems. However, the prevalence of non-SCI related conditions, such as diabetes, high blood pressure, and cardiac disease, was the same or less than the general population. This finding differs from the present study, which showed that for secondary complications and for all broad diagnostic categories, the SCI group had more physician contacts and more hospitalizations than the control group. An examination of the top 10 specific diagnoses for both groups revealed that physician contacts for hypertension were the same, however, the SCI group had 1.7 times the number of physician contacts for diabetes (data not shown). Differences in findings may relate to the diverse study population from Sweden whose duration of injury ranged from one to 44 years.

Few studies have reported on the utilization of physician services by persons with SCI. In the present study, the SCI group had a median of 52 physician contacts over the 6-year follow-up period. Almost all persons (99.1%) saw a family physician at least once during the follow-up period. After family physicians, internists (36.5%), physical medicine specialists (36.0%), and urologists (31.2%) were the physicians seen most often after the first year post-injury. Approximately 12% visited a psychiatrist over the 6-year follow-up. These results confirm those reported by Berkowitz et al. (1). In a survey of 758 persons who were at least three years post-injury, they found that 86.3% saw a physician at least once a year, with a mean of 18 visits per year. In the year prior to the survey, the most commonly visited physicians were urologists (45%), family physicians (44%), neurologists/neurosurgeons (31%), orthopedic surgeons (30%), and physical medicine specialists (27%). Approximately 10% of those surveyed had visited a psychiatrist in the previous year. Our findings also support those of Meyers et al. who conducted a survey of 96 people with high level SCI who were between one and 41 years post-injury (9). They found that 78% had seen a physician in the previous year. The median number of outpatient visits to a physician or nurse practitioner in the previous year was 4.0. Almost 50% reported one to five contacts, 39% reported six or more, and 8% reported seeing a physician or nurse practitioner at least once per week.

In the current study, the proportion of persons with SCI who were re-hospitalized following initial discharge were 22.5%, 29.4%, 14.9%, 16.0%, 13.8%, and 13.4% in years one through six, respectively. These findings are similar to those reported by Johnson et al. in a population-based study using self-report survey methodology. They interviewed SCI survivors from Colorado at their first, third and fifth year post-injury anniversaries and found that 27.0% of their cohort was re-hospitalized in the first post-injury year, 20.1% in year three and 18.8% in year five (4). In a cross-sectional study of Model SCI System patients who were between one and seven years post-injury, researchers found that 26% of patients had been hospitalized at least once in the previous year (10).

Other studies, however, have reported higher rates of re-hospitalization. Davidoff et al. followed patients from a Model SCI System centre for one year following discharge from initial rehabilitation and found that 39% were re-admitted at least once during the year (8). In a study of male veterans with SCI, Samsa et al. reported that between 42% and 50% (depending on level and extent of injury) were re-admitted to a Veterans Affairs hospital in the U.S. in the first year post-injury (11). This rate declined to between 30% and 47% in the fifth post-injury year. These higher rates may reflect a more severely injured patient population who continue to use the Model SCI or Veterans Affairs systems for follow-up care.

As has been shown in previous research, persons with SCI are at risk for secondary complications, not only during initial hospitalization but also in the years following discharge (2-4, 6, 31). Persons with SCI are treated for these conditions at significantly higher rates than their matched controls. While not all persons with SCI will require treatment for a secondary complication, it is a significant minority who will require follow-up care through the health system.

The current research showed that the SCI group received a diagnosis for depression 2.5 times more than the control group. While a confirmation of diagnosis was not possible using these methods, we are confident with these estimates given that the rate among the control group was 10.8%, which is almost identical (10.2%) to the estimated prevalence of affective disorders in the general population in Alberta (32). Previous research is equivocal as to the occurrence of depression following SCI. Among patients who were assessed during their initial rehabilitation, between 13.7% and 43.8% were reported to have depression (33-36). In a study that followed patients for two years after injury, researchers reported that 26.8% were clinically depressed (37). Among individuals who were between 1 and 44 years post-injury, Levi et al. reported that persons with SCI were more likely than the general population to report mental symptoms such as anxiety (OR=3.7), sleep disturbance (OR=3.5), and fatigue (OR=2.1). The present study found that 11.2% of patients were treated for depression during initial hospitalization, and an additional 38 (17.8%) were treated following discharge, for an overall rate of 22.1%. For all measures of mental disorders in this study, the SCI group used more services than the control group, suggesting a greater need for mental health care.

It is clear from this research that the need for health services by people with SCI continues long after they complete their initial hospitalization. These services are particularly important to prevent secondary complications. This requires ongoing multi-faceted efforts at maintaining contact with persons with SCI after their discharge into the community. Family physicians may be ideally suited to facilitate this ongoing contact. Our study showed that family physicians were visited most often after the first post-injury year and most individuals in our cohort contacted a family physician at least once following their injury. However, family physicians may not be familiar with the lifelong medical needs that are specific to a person with SCI (38). Thus, information packages tailored to family physicians who have patients with SCI may be an important service that could be developed by SCI specialists.

Multidisciplinary outreach services also have a role to play in the provision of information and support for many aspects of medical and social care for persons with SCI (39, 40). Because individuals tend to negate the possibility that 'silent' complications may be developing, they may be unwilling to take the time and expense to come back for regular evaluations (41). A follow-up system involving reminder cards or phone calls from family physicians, outreach services, and/or peer support groups might encourage persons with SCI to have annual physical examinations. The use of technology can help to increase access to a range of health professionals and services to SCI population and support the delivery of outreach services (42-44). For example, researchers from an SCI centre in Georgia have demonstrated that telehealth interventions can be used successfully to manage skin care and to promote general self-care among people with SCI (42, 43). Further research into what strategies may be best suited for this important group of patients is clearly needed.

Potential limitations of this research need to be discussed. First, data are not available on health care services that were provided outside the province of Alberta. It is not possible to determine the extent to which patients sought out-of-province care or the nature of services. This would result in an underestimate of service utilization for both the SCI and control groups. Second, the data sources do not provide information on neurological outcomes or functional recovery of persons with SCI, nor do they include measures of socioeconomic status, which might be associated with health status. This precluded an analysis of risk factors associated with utilization of health services. Notwithstanding the above concerns, to our knowledge this study represents the most comprehensive and extended picture of health care utilization by individuals with SCI. It is population-based, followed individuals from date of injury to six years post-injury, and includes data on all hospitalizations, fee-for-service physician contacts, home care services, and long-term care admissions in a large geographically defined region. The results of this study can be generalized to areas with similar populations.

3.5 Conclusion

SCI places a heavy burden on the health care system in the first six years following injury. Persons with SCI have higher rates of contact with the health care system compared with the general population, including hospitalizations, long-term care admissions, home care services, and physician contacts. Secondary complications, including urinary tract infections, decubitus ulcer, pneumonia and septicemia, continue to plague persons with SCI long after the acute trauma. In addition, other health care problems appear to be more common in this population. For example, psychological disorders are greater than those of the general population. Persons with SCI continue to be high users of the health care system long after the acute care phase. Ongoing follow-up care that addresses all aspects of physical and psychological well being, not just those directly related to the injury, is essential for individuals with SCI.

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Table 3.1. Demographic and injury characteristics of spinal cord injury patients injured in Alberta, Canada between April 1, 1992 – March 31, 1994 (N=233).

	Died during initial hospitalization (N=20)	Survived initial hospitalization (N=213)	Total (N=233)
Sex			
Male (No. (%))	11 (55.0%)	165 (77.5%)	176 (75.5%)
Place of residence			
Urban (No. (%))	8 (40.0%)	123 (57.7%)	131 (56.2%)
Age			
Median	70.5 yrs.	32.0 yrs.	34.0 yrs.
Interquartile range	41.5 - 82.5 yrs.	23.0 - 45.0 yrs.	24.0 - 48.0 yrs.
Cause of Injury (No. (%))			
Motor vehicle collisions	8 (40.0%)	108 (50.7%)	116 (49.8%)
Falls	9 (45.0%)	52 (24.4%)	61 (26.2%)
Struck by person/object		15 (7.0%)	15 (6.4%)
Sports & recreation		14 (6.6%)	14 (6.0%)
Other*	3 (15.0%)	24 (11.3%)	27 (11.6%)
Level & extent of injury (No. (%))			
C 1 – 4			
Complete	1 (5.0%)	3 (14.1%)	4 (1.7%)
Incomplete	1 (5.0%)	21 (9.9%)	22 (9.4%)
Unspecified	4 (20.0%)	28 (13.1%)	32 (13.7%)
C 5 – 8			
Complete	2 (10.0%)	11 (5.2%)	13 (5.6%)
Incomplete		29 (13.6%)	29 (12.4%)
Unspecified	3 (15.0%)	14 (6.6%)	17 (7.3%)
Thoracic			
Complete	1 (5.0%)	25 (11.7%)	26 (11.2%)
Incomplete		18 (8.5%)	18 (7.7%)
Unspecified	1 (5.0%)	12 (5.6%)	13 (5.6%)
Lumbar/Sacral/Cauda Equina			
Unspecified	3 (15.0%)	38 (17.8%)	41 (17.6%)
Multiple/Unspecified	4 (20.0%)	14 (6.6%)	18 (7.7%)
Associated injuries (No. (%))			
Traumatic brain injury (TBI)	1 (5.0%)	10 (4.7%)	11 (4.7%)
Multiple, including TBI	4 (20.0%)	36 (16.9%)	40 (17.9%)
Multiple sites, no TBI	6 (30.0%)	34 (16.0%)	40 (17.9%)
Head/neck/face		7 (3.3%)	7 (3.0%)
Torso	1 (5.0%)	33 (15.5%)	34 (14.6%)
Extremities		10 (4.7%)	10 (4.3%)
No other injuries	8 (40.0%)	83 (39.0%)	91 (39.1%)

*Includes other transportation, intentional, machinery, unspecified

Table 3.2. Hospital utilization for spinal cord injury patients in Alberta, Canada: initial hospitalization and re-hospitalizations over 6-years of follow-up.

	C 1 – 4	C 5 – 8	Thoracic	Lumbar/Sacral/ Cauda Equina	Unspecified	Total
Initial hospitalization	(N=58)	(N=59)	(N=57)	(N=41)	(N=18)	(N=233)
Length of stay						
Total bed-days	3,461	4,192	4.530	1,796	241	14,220
Median (days)	19	25	86	23	5	26
Interquartile range (days)	3 to 88	8 to 138	18 to 119	10 to 80	3 to 14	6 to 98
Deaths during initial hosp.	6	5	2	3	4	20
Re-hospitalizations	(N=52)	(N=54)	(N=55)	(N=38)	(N=14)	(N=213)
No. of people admitted	32	28	31	23	9	122
No. of re-hospitalizations	94	102	86	52	33	365
Length of stay						
Total bed-days	948	875	747	268	616	3,454
Median (days per admission)	5	4	5	3	4	4
Interquartile range (days)	2 to 9	2 to 9	2 to 9	1 to 7	2 to 7	2 to 9

Table 3.3. Physician contacts for individuals with spinal cord injury over 6-years of follow-up.

	C 1 – 4	C 5 – 8	Thoracic	Lumbar/Sacral /Cauda Equina	Unspecified	Total
Year 1 (N=233)						
Median visits (#)	21	21	28	24	11	22
Interquartile range	12 to 37	12 to 36	19 to 50	15 to 38	6 to 30	12 to 37
Years 2 – 6 (N=211)						
Median visits (#)	37	27	30	29	30	29
Interquartile range	12 to 85	10 to 49	13.4 to 56.0	17 to 48	20 to 559	13 to 57
All years (N=233)						
Median visits (#)	55	51	64	51	40	52
Interquartile range	22 to 122	22 to 85	34 to 106	32 to 82	20 to 64	26 to 97

Table 3.4. Secondary complications for persons with spinal cord injury over 6-years of follow-up (N=233).

	Initial Hosp.	Year 1*	Year 2	Year 3	Year 4	Year 5	Year 6	All years
Urinary Tract Infection								
During hospitalization (# people)	77 (33.0%)	7	11	3	6	8	5	86†
Physician contacts (# people)		22	26	18	21	22	21	63‡
Physician contacts (# visits)		54	41	40	61	43	68	307
Decubitus Ulcer								
During hospitalization (# people)	25 (10.7%)	2	10	2	4	3	1	31†
Physician contacts (# people)		9	9	9	7	9	6	29‡
Physician contacts (# visits)		44	62	18	22	43	32	221
Pneumonia								
During hospitalization (# people)	31 (13.3%)	6	6	3	5	1	4	49†
Physician contacts (# people)		40	11	10	12	6	8	64‡
Physician contacts (# visits)		138	31	21	19	8	21	238
Septicemia								
During hospitalization (# people)	17 (7.3%)	2	1	2	2	1	3	25†
Physician contacts (# people)		7	2	1	2	1	5	17‡
Physician contacts (# visits)		10	7	1	4	2	13	35
Depression								
During hospitalization (# people)	26 (11.2%)	4	2	2	5	3	3	35†
Physician contacts (# people)		27	23	15	18	17	18	57‡
Physician contacts (# visits)		98	70	84	142	154	74	622

*For treatment during hospitalization, Year 1 refers to the remainder of the first post-injury year. For Physician contacts, Year 1 refers to contacts made anytime during the first post-injury year.

†Number of individuals who were hospitalized at least once; some were hospitalized more than once over the 6-years.

‡Number of individuals had at least one physician contact over the 6 years (at least two contacts for depression).

Figure 3.1. Hospitalizations for persons with spinal cord injury and their matched controls over 6 years of follow-up (Year 1 for the SCI group includes hospital admissions in the remainder of the first post-injury year).

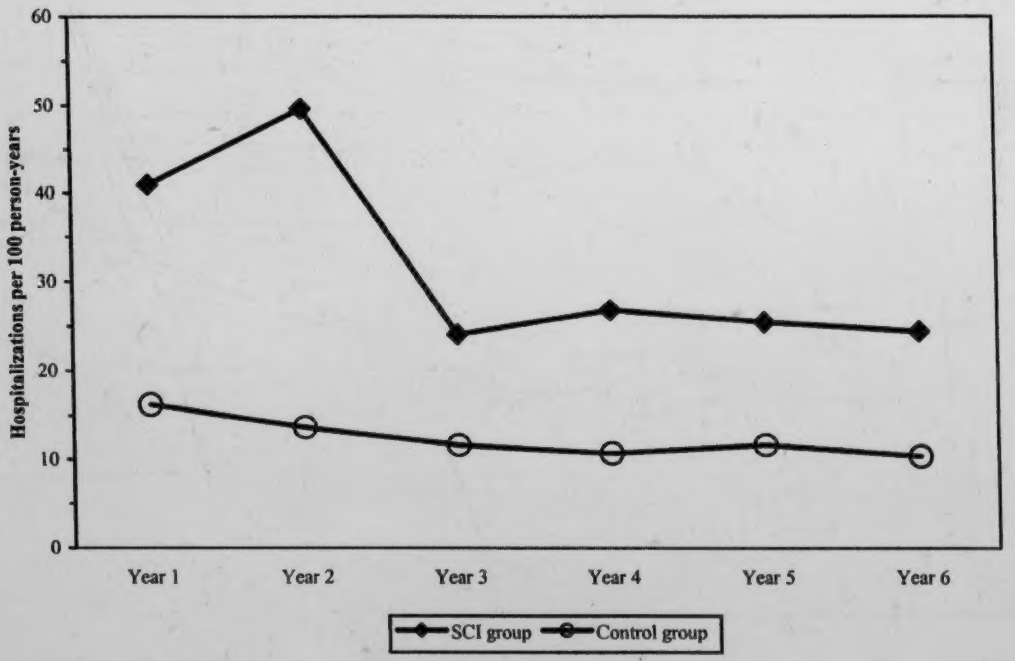
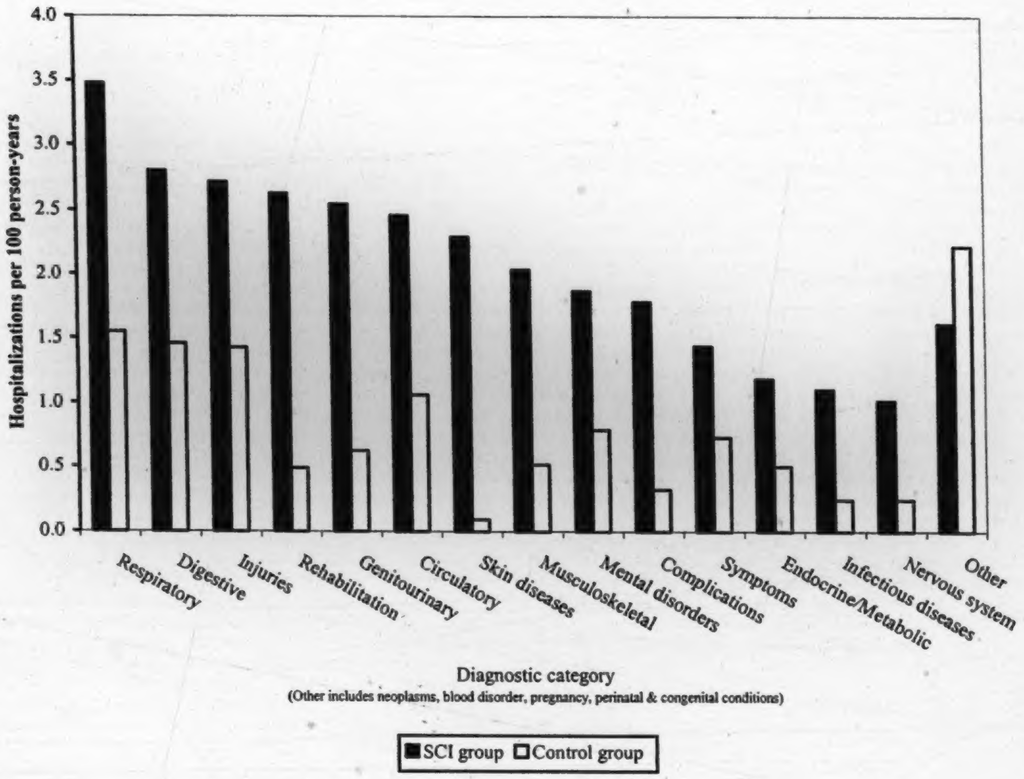


Figure 3.2. Hospitalizations by diagnostic category for SCI patients and their matched controls over 6-years of follow-up following initial hospitalization for the SCI group. Diagnostic category is based on the principal diagnosis for each admission.



(Other includes neoplasms, blood disorder, pregnancy, perinatal & congenital conditions)

Figure 3.3. Physician contacts by specialty by persons with spinal cord injury and their matched controls over 6-years of follow-up.

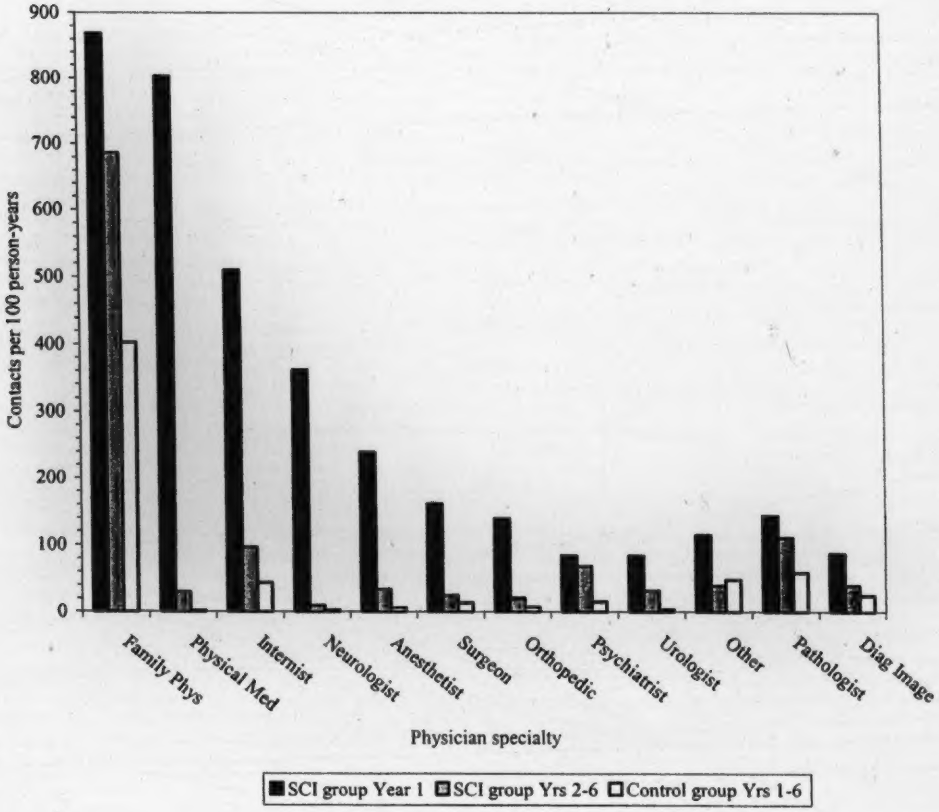


Figure 3.4. Physician contacts by diagnostic category for persons with spinal cord injury and their matched controls over 6-years of follow-up.

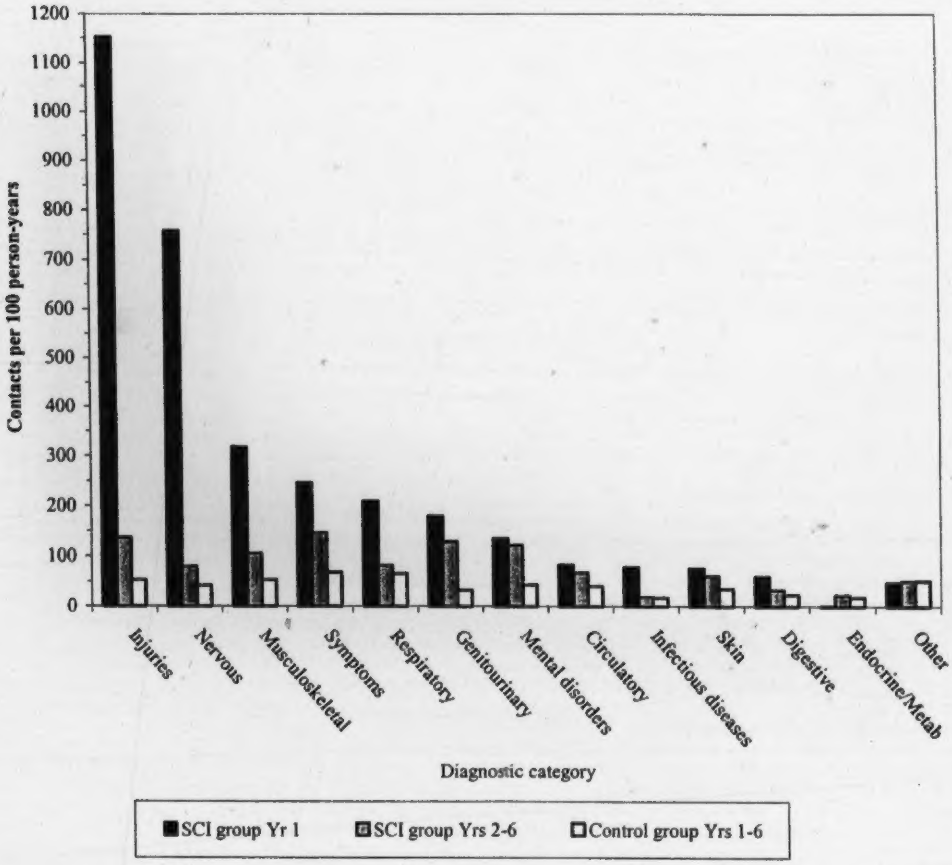
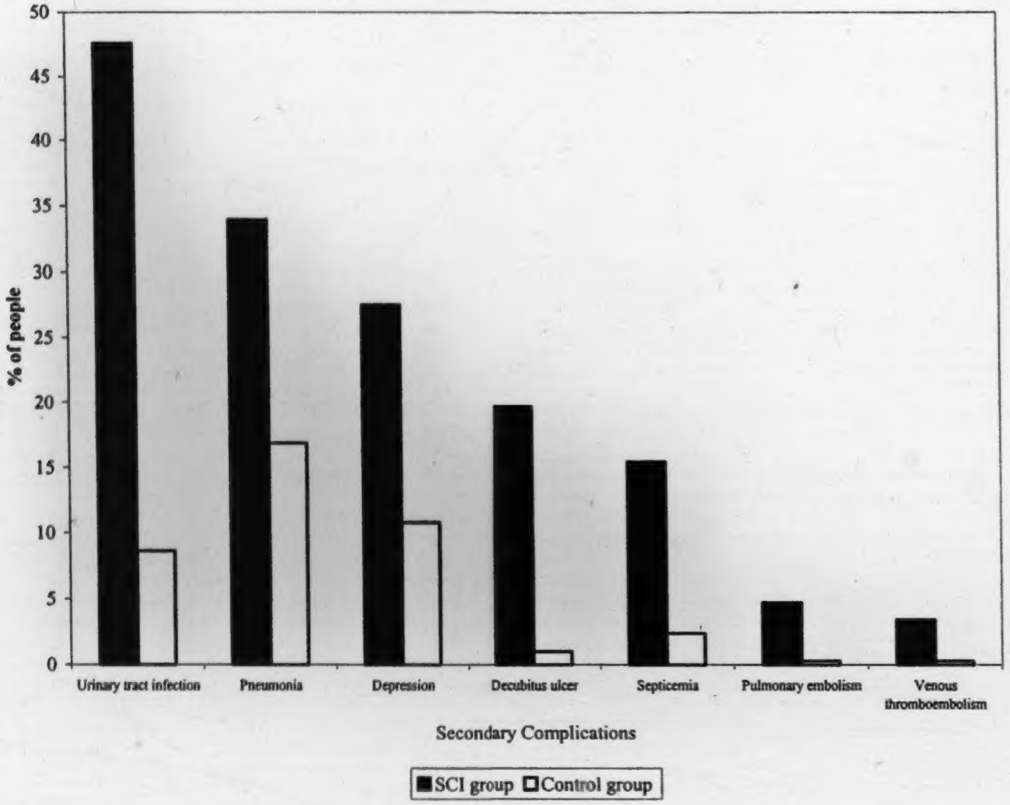


Figure 3.5. Proportion of spinal cord injury group and control group diagnosed with a secondary complication over 6-years of follow-up.



Chapter 4

Direct Health Care Costs Following Traumatic Spinal Cord Injury

4.1 Introduction

Persons who sustain a traumatic spinal cord injury (SCI) will incur significant initial and ongoing expenses for medical treatment and rehabilitation. Previous research has shown that in the months and years following acute trauma, persons with SCI are at risk for a number of secondary complications, which can result in frequent contact with physicians and hospitalizations (1-3). Individuals who are permanently disabled may require assistance with activities of daily living. Ongoing care, secondary complications and hospital admissions are costly (1, 4, 5). Since there is currently no cure for SCI, and with life expectancies increasing for individuals with SCI (6, 7), the ongoing health care costs will be substantial. Accurate cost data are essential in order to assist planners to forecast health care costs due to SCI, as well as to enable researchers in the field of injury prevention to benchmark costs in order to identify potential savings associated with primary, secondary and tertiary prevention initiatives.

While previous research has provided cost estimates for SCI, often studies suffer from methodological limitations. For example, many studies reflect the experiences of a subset of the SCI population, such as patients treated at a single health care centre (8), by a single service provider (4), or injured by a specific cause (9). Some studies have relied on patient recall to identify utilization of health services (1, 5), or calculated costs using secondary data sources such as government or trade association publications (1, 8).

The present study addresses these limitations using a population-based, cohort design to follow individuals who sustained a SCI in Alberta, Canada from their date of injury to six years post-injury. Cost data were derived from administrative data from the Alberta Ministry of Health and Wellness. Direct health care costs were estimated for hospital admissions, physician services, home care services, and long-term care. The primary objectives were:

1) To quantify the direct health care costs following SCI during initial hospitalization and for six years post-injury;
2) To estimate attributable costs per person during first six years post-injury.

4.2 Methods

4.2.1 Study location

Alberta is a province located in western Canada and occupies an area of approximately 661,000 square kilometers. In 1993 the population was estimated as 2.7 million, of which 75% lived in urban areas. Alberta has a universal publicly funded health care system that guarantees access to medically necessary hospital and medical services for all residents of the province. Virtually all (>99%) Alberta residents are registered with the system (10).

4.2.2 Definition of SCI

SCI was defined as the occurrence of an acute traumatic lesion of neural elements in the spinal canal (spinal cord and cauda equina) resulting in resolving or permanent neurological deficit. Cases were identified by the *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) diagnostic codes for SCI: 806.x (fracture of the vertebral column with SCI) or 952.x (SCI without evidence of spinal bone injury). The use of these two ICD-9-CM codes was based on the "Uniform Data Systems Cases Definition" recommended by the U.S. Centers for Disease Control and Prevention (11). This definition has been used extensively in trauma registries and surveillance systems to identify SCI (5, 12-14).

4.2.3 Inclusion criteria and case identification

A search of the Alberta Ministry of Health and Wellness Inpatient database (see below under 'Data sources') identified Albertans who were hospitalized for SCI over two fiscal years (April 1, 1992 – March 31, 1994). The inclusion criteria were: 1) admission to a hospital in Alberta between April 1, 1992 and March 31, 1994, with an ICD-9-CM code for SCI, 2) transfer to an acute care hospital in Calgary or Edmonton, the two major cities in the province, 3) an external cause of injury code (E code) consistent with traumatic SCI, and 4) Alberta residency at the time of injury. In Alberta, it is the practice that all severely injured patients are transferred from smaller, rural hospitals to a large urban acute care centre. It was assumed that all patients with a suspected SCI would have been transferred to Edmonton or Calgary for confirmation of diagnosis and treatment. In a previously identified cohort, this was 89.0% of all patients who had an ICD-9-CM code for SCI in Alberta (15). Patients were excluded if they had a subsequent diagnosis of a "conversion" disorder (ICD-9-CM code 300.11).

4.2.4 Control group

For comparison with the general population, each SCI case was matched to five controls randomly selected from the Alberta Health Care Insurance Stakeholder Registry (see below under 'Data sources'). Controls were matched with SCI cases for age, sex and region of residence (to control for distance and access to health services). Individuals were not eligible to be controls if they sustained a SCI at any time during the follow-up period or if there was evidence of a prior SCI (ICD-9-CM codes 952.x, 806.x or 907.2 [late effect of SCI]).

4.2.5 Follow-up period

Data on health care utilization and direct health care costs were collected from date of injury for each SCI case to six years post-injury. For each individual in the control group, data were collected from the date of SCI of their matched cases to six years after the date of injury. Deaths and losses to follow-up were confirmed in the Stakeholder Registry (see below). Persons who were lost to follow-up were presumed to have moved from the province.

The initial hospitalization period refers to the episode of care in the hospital system from date of SCI to the first definitive discharge to the community or to a long-term care facility. It includes admissions to rural hospitals prior to transfer to an acute care hospital in Edmonton or Calgary, acute care hospitalization, and inpatient rehabilitation.

4.2.6 Data sources

Data for this study were gathered from the Alberta Ministry of Health and Wellness (10). The Ministry maintains computerized records of all hospital and medical services in Alberta. Every Alberta resident has a unique personal health number, which is used to link records among different data sources within the Ministry. Records from five databases were used to compile information on individual encounters with the Alberta health care system during the 6-year study period. The data sources were:

Alberta Health Care Insurance Stakeholder Registry (Stakeholder Registry): This database contains demographic information about Albertans registered with the health care system.

Canadian Institute for Health Information (CIHI) Hospital Inpatient database (Inpatient database): Records of all hospitalizations in Alberta are collected in the Inpatient database. Separation abstracts are completed for each admission by trained medical records nosologists and contain admission and discharge dates, up to 16 ICD-9-CM diagnostic codes, up to 10 ICD-9-CM procedure codes, and Refined Diagnosis Related Group (RDRG) weights. RDRGs are used as a proxy measure for average resources required for the specific hospitalization (16).

Alberta Health Insurance Plan Payment Data (Claims database): This is a database of fee-for-service claims submitted by physicians and other health service providers (e.g. optometrists and physical therapists) in Alberta for the provision of medically required services. For the purposes of this research, only physician claims are reported. Claims for diagnostic services (pathology and diagnostic imaging) were excluded for all years of follow-up due to changes in the billing for these services in 1995. Data from the Claims database include up to three ICD-9-CM diagnostic codes, physician specialty, procedure codes, and the professional fees paid for each service claim.

Home Care Information System (Home care): The database provides information on clients receiving services provided under the home care program including nursing care, meal services, and other support for activities of daily living. Data include date of service, total hours of service, and service duration.

Long Term Care Resident Classification (Long-term care): Data are collected for all residents in long-term care facilities during the annual assessment period. Individuals are included if they were classified during the previous year or were resident at the time of assessment. In Alberta, residents are classified into one of seven levels of care that reflect the expected hours of nursing care provided each day (17).

4.2.7 Health care costs

Hospitalization costs are based on the RDRG and the length of stay for each separation claim from the Inpatient database (Appendix G). Cost estimates were derived from the *Cost List for Manitoba Health Services* (18), which provides cost estimates of inpatient hospital care in the province of Manitoba, Canada. For each RDRG, the cost list provides an average cost per day and a marginal cost per day. To adjust for differences in service delivery and practice patterns between Alberta and Manitoba, relative Alberta hospital costs were calculated using an index factor based on the costs per weighted case for each province taken from the *National List of Provincial Costs for Health Care: Canada 1997/8* (19). The cost per weighted case for each province was estimated by dividing the total inpatient cost by the total weighted cases for all participating hospitals. The index factor to calculate adjusted Alberta costs was 1.23. The calculation for the Alberta cost for each RDRG was: *(average cost per day x length of stay x 1.23)*. For patients whose stay in hospital was longer than the Alberta average length of stay for each RDRG, the calculation was: *((average cost per day x average length of stay) + (number of days beyond mean length of stay x marginal cost per day)) x 1.23*.

Actual costs of physician services were included in the data abstracted from the Claims database and are reported for each service claim. Fee-for-service payments to physicians are based on the provincial fee schedule (20).

Home care costs were calculated using the number of service hours and the hourly rates for each service, which are reported in the Home Care database. Costs included labor costs of the professionals who provide direct care in the home. Costs for equipment and supplies were not included.

Costs for long-term care were based on a per diem payment that has been allocated for the level of care required by residents in long-term care facilities. The per diem fee covered both the residential (room and board) and the professional care components (19). Length of stay is not available from the long-term care database and was estimated as follows. For patients who died, length of stay was calculated from date of admission to date of death. For patients who were in long-term care for multiple years, length of stay was 365 days for each year. For patients who were discharged from long-term care (i.e. no further annual assessment dates), a mid-year discharge was assumed in the year following the last annual assessment and, therefore, length of stay was estimated as six months (183 days).

For comparison purposes, all costs were converted to 2002 dollars, using the Consumer Price Indices for the health care service basket for Alberta from 1992 to 2002. Consumer Price Index values were obtained from CANSIM databases from Statistics Canada (21). Costs are reported in Canadian dollars (2002 $CDN).

4.2.8 Analyses

Descriptive statistics for demographic and injury characteristics for SCI patients are presented using frequencies and percentages for categorical data, and medians and interquartile ranges (IQR) for continuous variables.

Total observed costs are reported as mean annual costs. Per person costs were calculated by dividing the aggregate observed costs in each expenditure category by the total number of individuals who sustained a SCI during the study period.

Using data for the SCI and the control groups, multivariable linear regression analysis was used to estimate costs attributable to SCI during the first six years post-injury (22). The dependent variable was the total cost per person over all follow-up years. Independent variables included age, sex, level and severity of injury, year of injury, and a variable that identified whether an individual belonged to the SCI or the control group. First and second order interactions were also tested. Predicted costs for each SCI case and control were calculated based on the best fitting regression equation. From these predicted costs, the mean cost per person was calculated. Because the dependent variable was heavily skewed, bootstrapping methods were used to estimate standard errors for the regression equation (23, 24). Mean attributable costs were calculated as the difference between the mean cost per person for the SCI group and the mean cost per person for the control group. Results are presented as mean attributable costs with 95% confidence intervals (95% CI).

4.2.9 Ethics

This study was approved by the Health Research Ethics Board (B: Health Research), at the University of Alberta, Edmonton, Canada. To maintain the confidentiality of patients, all personal identifiers were removed prior to the release of data from the Alberta Ministry of Health and Wellness.

4.3 Results

4.3.1 Demographic and injury characteristics

Between April 1, 1992 and March 31, 1994, a total of 233 patients met the inclusion criteria for traumatic SCI and were included in the study (Table 4.1). The mean incidence rate for SCI was 43.5 per million population per year (95% CI: 37.9, 49.1). The median age for the total sample was 34.0 years (IQR 24.0 to 48.0), with ages ranging from 9 to 95 years. Overall, 75.5% were male. Motor vehicle collisions accounted for the greatest proportion of SCI (49.8%), followed by falls (26.2%). One hundred and twenty-one (51.9%) individuals sustained an injury at the cervical level, while 101 (43.3%) sustained an injury at the thoracic, lumbar, sacral, or cauda equina level. Forty-three (18.5%) of the injuries were classified as complete. Twenty (8.6%) SCI patients died during their initial hospitalization and an additional 16 died during the 6-year follow-up period (Table 4.1). In addition to those who died during the follow-up period, 20 (8.5%) were lost to follow-up.

4.3.2 Total observed costs

The overall costs for initial hospitalization following SCI were substantial. Each year in Alberta, the initial acute care and inpatient rehabilitation costs for newly injured SCI patients were approximately $6.3 million (2002 $CDN). The mean cost per person ranged from $15,400 to $144,600, depending on level and severity of SCI (Table 4.2). Following initial hospitalization to six years post-injury, an additional $2.9 million in direct health care costs were incurred for these newly injured patients. Over the entire study period, hospitalizations were the highest category of expenditures ($7.3 million; 78.7%), followed by physician services ($786,000; 8.5%). During the first post-injury year and in the subsequent five years, costs were greatest for persons with complete tetraplegia and complete paraplegia (Table 4.2).

4.3.3 Attributable costs

The predicted costs for each SCI case and control were derived from the best fitting regression model (Table 4.3). The independent variables included in the final model were age, sex, SCI/control, year (dichotomized into Year 1 and Years 2 – 6), severity of injury (dichotomized into incomplete and complete) and first and second interaction terms for SCI/control, severity and year (Appendix H). The variable for year of injury was dichotomized following examination of the mean predicted costs for each follow-up year, which showed no significant differences in costs for years two through six. Similarly, the severity of injury variable was collapsed as there were no significant differences in predicted costs when the level of injury was included. For example, costs for persons with complete tetraplegia and complete paraplegia were not significantly different and were therefore combined. The value of R^2 for the model was 0.40.

In the first year post-injury, costs attributable to SCI were $121,600 per person (95% CI: $121,333, $122,940) for individuals with complete injuries and $42,100 per person (95% CI: $39,207, $42,935) for persons with incomplete injuries. In the subsequent five years, annual attributable costs were $5,400 per person (95% CI: $5,186, $5,960) and $2,800 per person (95% CI: $2,723, $2,972), respectively.

4.5 Discussion

This population-based study examined direct health care costs following traumatic SCI over a six-year period in a Canadian province with universal health care and centralized health databases. Information on costs was comprehensive and included hospitalization, physician services, home care services, and long-term care. The results showed that health care costs during the first post-injury year were considerable – between $42,000 and $121,600 more per person than controls drawn from the general population, depending on the severity of the SCI. In the subsequent five years, persons with SCI can be expected to generate costs that are three to six times greater than the general population, depending on the severity of the SCI.

Direct comparisons between these results and previous research are complicated by differences in study populations, data sources, and methods; however, some patterns can be observed. Berkowitz et al. investigated the costs accrued by a probability sample of 758 persons with SCI living in the United States (1, 25). The average duration of injury was 14 years. Participants responded to a detailed questionnaire that included questions about their utilization of health services during the first two years post-injury and in the year prior to the interview. Costs were derived from secondary sources, including government, industry, and trade association publications. The average expenditures for initial hospitalization (the first 2 years post-injury) were $95,000 (1988

$US). After recovery from acute care and rehabilitation, the average annual costs for medical services were $7,900. Personal assistance costs and the costs of institutional care amounted to $6,200 per person. Expenditures were greatest for persons with complete and incomplete tetraplegia during initial hospitalization and for ongoing medical services, personal assistance and institutional care.

DeVivo et al. conducted a one-year prospective study of a random sample of 508 previously injured and 227 newly injured Model SCI System patients (4). Utilization and charge data were collected through telephone interviews and National SCI Database abstraction. The authors reported mean first year costs of $98,000 (1992 $US) per person. The mean annual follow-up costs were $24,000 per person. For both first-year and ongoing costs, individuals with high and low tetraplegia with no functional motor activity incurred the greatest expenditures. Attendant care, nursing home care, equipment and supplies represented 73% and 67% of ongoing annual costs for those with high and low tetraplegia, respectively.

Johnson et al. conducted a prospective study with a population-based cohort of 115 individuals who sustained a traumatic SCI in Colorado (5). Cost data for the first two years post-injury were collected through interviews to determine use of medical services; billing information was obtained directly from providers. Total costs over the two-year follow-up period were $21.7 million (1992 $US). The initial hospitalization phase accounted for 71% of total dollars spent. The mean cost for initial hospitalization was $134,000. The mean follow-up charges were $58,000. Persons with tetraplegia accounted for 23% of persons injured, but utilized 46% of the initial hospitalization dollars and 61% of the follow-up costs. A high percentage of follow-up cost was due to the cost of in-home care.

The current Alberta study confirms some of the results from previous research. The costs for initial acute care and rehabilitation following SCI are substantial (1, 4, 5, 25). In our study, they represented 68.2% of the total observed costs over six years. During the initial hospitalization period, those with complete tetraplegia and paraplegia had highest costs. This is consistent with the results reported by Johnson et al. (5) and DeVivo et al. (4). Following the first post-injury year, we found that costs were greatest for individuals with complete tetraplegia, followed by those with complete paraplegia. This finding confirms that reported by DeVivo et al. (4).

Potential limitations of this research need to be discussed. First, several categories of expenditures are not included in the cost estimates (pre-hospital costs, non-physician services, diagnostic services, equipment and supplies to support activities of daily living, outpatient drugs). Therefore, costs will be underestimated; however, we are unable to determine the degree of underestimation. Second, the value of R^2 for the best fitting regression model was 40%. This low value indicates that there are many other factors associated with health care costs that are not accounted for in the model. However, low R^2 values are not unexpected in regression analysis of utilization data and 40% is within acceptable values (26).

Notwithstanding the above concerns, this study has provided a useful estimate of the economic impact of SCI in a defined geographical area. Use of administrative data has enabled us to estimate costs that are population-based, attributable to SCI, based on direct observation, and inclusive of downstream events. The results will be useful to planners to forecast health care costs due to SCI and to researchers conducting studies on the economic value of the prevention of SCI.

4.6 Conclusion

SCI is costly and places a heavy burden on the health care system. Attributable costs in the first year post-injury were estimated at $121,600 per person with a complete SCI, and $42,100 per person with an incomplete lesion. In the subsequent five years, annual attributable costs were $5,400 and $2,800 for persons with complete and incomplete SCIs, respectively.

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Table 4.1. Demographic and injury characteristics of SCI patients injured in Alberta, Canada between April 1, 1992 and March 31, 1994 (N=233).

Age (Median)	34.0 yrs
Interquartile range	24.0 – 48.0
Sex (Male)	176 (75.5%)
Place of residence (Rural)	102 (43.8%)
Cause of injury	
Motor vehicle collision	116 (49.8%)
Falls	61 (26.2%)
Struck by person/object	15 (6.4%)
Sports & recreation	14 (6.0%)
Other*	27 (11.6%)
Level & extent of injury	
Tetraplegia complete	17 (7.3%)
Tetraplegia incomplete/unspecified	104 (44.6%)
Paraplegia complete	26 (11.2%)
Paraplegia incomplete/unspecified	75 (32.2%)
Unspecified	11 (4.7%)
Associated injuries	
Traumatic brain injury	51 (21.9%)
Other injuries	91 (39.1%)
No other injuries	91 (39.1%)
Deaths	36 (15.5%)

*Includes other transportation, intentional, machinery, unspecified.
% do not total 100% due to rounding

Table 4.2. Observed utilization and direct health care costs per person by level and severity of SCI (2002 $CDN).

	Tetraplegia Complete (N=17)	Tetraplegia Incomplete (N=104)	Paraplegia Complete (N=26)	Paraplegia Incomplete (N=75)	Unspecified (N=11)
Initial hospitalization					
Hospitalizations	$135,200	$40,000	$93,600	$36,400	$13,300
# bed days	153	49	123	42	17
Physician services	$9,400	$2,700	$6,100	$3,000	$2,100
# contacts	53	16	38	15	7
Mean costs	$144,600	$42,700	$99,700	$39,400	$15,400
Remainder of year 1					
Hospitalizations	$5,000	$1,700	$2,800	$1,100	$6,300
# bed days	10	3	4	2	18
Physician services	$800	$500	$600	$600	$500
# contacts	10	10	10	12	7
Home care services	$500	$300	$900	$100	0
# hours	21	19	34	7	0
Long-term care	0	$500	$600	$300	0
# persons	0	31	2	1	0
Total costs for year 1	$150,900	$45,700	$104,600	$41,500	$22,200
Years 2 – 6					
Hospitalizations	$15,800	$5,500	$9,400	$4,600	$4,900
# bed days	23	8	15	6	7
# admissions	4	1	2	1	0.5
Physician services	$4,300	$2,200	$2,200	$2,700	$1,500
# contacts	69	40	35	48	34
Home care services	$32,900	$3,300	$6,400	$1,000	$6,800
# hours	1,923	209	375	61	469
Long-term care	$600	$4,800	$6,700	$3,300	0
# persons	1	7	1	2	0
Total costs for years 2 – 6	$53,600	$15,800	$24,700	$11,600	$13,200

Table 4.3. Mean attributable direct health care costs (2002 $CDN).

		Complete injuries	Incomplete injuries
Year 1			
	SCI group	$122,900	$43,400
	Control group	$1,300	$1,300
	Attributable costs	**$121,600**	**$42,100**
Years 2 – 6			
(costs per year)	SCI group	$6,400	$3,800
	Control group	$1,000	$1,000
	Attributable costs	**$5,400**	**$2,800**

Chapter 5

General Discussion and Conclusion

5.1 Overview

The preceding chapters have reviewed the previous research on traumatic spinal cord injury (SCI), described the magnitude and pattern of SCI in Alberta, the utilization of health services for six years following injury, and the direct health care costs associated with those services using comprehensive Alberta data. The review of the literature, presented in Chapter 1, revealed the paucity of Canadian research on the epidemiology of SCI and on the utilization and cost of health resources following SCI. While there has been relevant research internationally, it is unclear whether results from other countries can be generalized to the Canadian setting.

Chapter 2 describes the incidence and pattern of SCI in Alberta. To date, the results represent the most comprehensive study on SCI in Canada. Population-based data were gathered from three centralized provincial sources over three years (April 1, 1997 – March 31, 2000): administrative data from the Alberta Ministry of Health and Wellness, records from the Alberta Trauma Registry, and death certificates from the Office of the Medical Examiner. The use of these sources enabled complete case ascertainment including pre-hospital fatalities, persons with resolving neurological deficits, and those whose injury resulted in permanent neurological impairment. No other Canadian study has included pre-hospital fatalities. The annual incidence rate for SCI in Alberta was 52.5 per million population (95% CI: 47.7, 57.4) when pre-hospital fatalities are included, and 44.3 per million (95% CI: 39.8, 48.7) when only those who survived to hospital admission are included. Rural residents are 2.5 times as likely to be injured as urban residents. Motor vehicle collisions (MVC) account for 56.4% of injuries, followed by falls (19.1%). The highest incidence of motor vehicle-related SCI occur to those between the ages of 15 and 29 years (60 per million population per year). Fall-related injuries primarily occur to those older than 60 years (45 per million population per year). This pattern of injury is similar to that reported by population-based studies from other countries (1-5). The Alberta SCI incidence rate for those admitted to hospital is within the range of recent Canadian reports from Ontario (6) and the National Trauma Registry (7).

Results from Chapter 3 document the magnitude and nature of health service utilization by a cohort of individuals who sustained a SCI in Alberta between April 1, 1992 and March 31, 1994. Administrative data from Alberta Health and Wellness were compiled to provide a complete picture of health care use, including hospitalizations, physician contacts, long-term care, home care services, and treatment for secondary complications. Through the data, 233 individuals with SCI and 1165 matched controls were followed for six years. Controls were randomly selected from the general population of Alberta and matched for age, sex, and region of residence. Compared with the control group, persons with SCI were re-hospitalized 2.6 times more often and spent 3.3 times more days in hospital. They also had 2.7 times more contacts with physicians and required 30 times more hours of home care services. Over the six-year follow-up period, 47.6% of individuals with SCI were treated at least once for a urinary tract infection, 33.8% for pneumonia, 27.5% for depression, and 19.7% for decubitus ulcer. The proportions of people with SCI who received treatment for these conditions were significantly greater than the control group. The current research found that 57% of individuals were re-hospitalized at least once following initial hospitalization, which is within the range of 19% (8) to 76% (9) reported in earlier studies. Readmission rates declined over the six year follow-up period, which has also been reported in previous research (8, 10). Only one other study has examined, in detail, the utilization of physician services (11). The pattern of utilization was consistent with that found in the current study.

Chapter 4 quantifies the direct health care costs following SCI for the cohort of patients that was included in Chapter 3. Results show that the economic impact of SCI is high. Not surprisingly, severity of injury (complete vs. incomplete) largely determines the cost of care. Costs attributable to SCI in the first post-injury year range from $42,000 per person (95% CI: $39,207, $42,935) for those with incomplete lesions, to $121,600 (95% CI: $121,333, $122.940) per person for those with complete lesions. Annual attributable costs over the subsequent five years are $2,800 (95% CI: $2,723, $2,972) and $5,400 (95% CI: $5,186, $5,960) per person per year for those with incomplete and complete injuries, respectively. This is the first Canadian population-based study to examine acute care and ongoing costs following SCI. Prior to this study the most detailed examination of costs and utilization following SCI was a study by Tator et al. (12). However, their report was limited to the acute care phase and to patients admitted to a single spinal injury unit between 1974 and 1981. The results of the current study support the findings of previous researchers who reported that persons with complete tetraplegia and paraplegia incurred the highest costs (13, 14).

Potential limitations of this research need to be discussed. First, without access to all medical charts for patients, it is impossible to confirm that SCI was a true diagnosis. While the selection criteria and coding for this study were validated through chart review, there is the possibility of misclassification of cases due to coding error or incomplete data entry. Second, the exclusion of patients who were admitted to a rural hospital but were not subsequently transferred to a trauma centre may have missed individuals with rapidly resolving neurological deficits and would result in an underestimate of cases. Third, the data on level and extent of SCI reflect discharge diagnoses following initial hospitalization, and do not reflect neurological outcomes or functional recovery that may have occurred following discharge. Furthermore, the data do not provide any information on health-related quality of life. Therefore, it is impossible to assess the impact that disability, morbidity and use of health care services may have on individuals with SCI. Fourth, several categories of health care services are not included (pre-hospital costs, non-physician services, diagnostic services, equipment and supplies to support activities of daily living, outpatient drugs). Therefore, the estimates of health service utilization and health care costs will be underestimated.

Notwithstanding the above concerns, this research has clearly demonstrated the use and value of population-based, uniformly coded, linked administrative data in determining the utilization and cost of health care services for specific identifiable illnesses or injuries. Specifically, this study has provided the most comprehensive and current examination of SCI epidemiology and direct health care costs in Alberta and Canada. The results will be useful to researchers in the field of injury prevention to identify risk factors and to implement targeted prevention strategies. In addition, researchers conducting studies on the economic value of injury prevention programs can use the per-person costs to obtain an estimate of the savings due to various interventions. This research also provides evidence to support work of health professionals and advocacy groups to address the long-term health needs of persons with SCI. The results clearly document the need for ongoing follow-up care for individuals with SCI that address all aspects of physical and psychological well-being, not just those that are directly related to the injury. In addition, health planners can use the results of this research to forecast direct health care costs associated with SCI.

5.2 Recommendations and future direction

5.2.1 Research-related recommendations

In Alberta, the Office of the Medical Examiner collects a wealth of data on sudden deaths, including detailed information on the circumstances surrounding the death. This information can be used to support injury prevention programs; however, access to the data is currently difficult due to lack of standardization in the terminology used to describe the cause of death. The development of a uniform coding system to identify the cause of death within the Office of the Medical Examiner would facilitate future research.

The long-term care database maintained by Alberta Health and Wellness does not include a record of discharge dates for residents. In order to determine the length of stay in long-term care, it is necessary to model the length of stay using the annual assessment date. The inclusion of discharge dates in this database would enable more accurate estimates of utilization and costs.

Access to additional health care data through Alberta Health and Wellness would enhance future research using administrative data. In particular, the ability to link the Personal Health Number from the Alberta Health Care Insurance Stakeholder Registry (15) with data on outpatient drugs, outpatient rehabilitation services, and utilization of aids to daily living would be useful. Enhancements to the Home Care databases may be the most appropriate means of addressing the last two categories.

This research showed that contacts with the health care system for mental health disorders were considerably higher among the SCI population than the general population. There is limited research that has systematically documented the broad range of psychiatric morbidity following SCI (16, 17). Further examination of administrative data may provide valuable information on the pattern and magnitude of health care utilization associated with mental health disorders.

5.2.2 Intervention-related recommendations

Since there is currently no cure for SCI, primary prevention efforts are paramount. The data in Alberta suggest that the strongest efforts at preventing SCI should focus on motor vehicle crashes, males of all ages, adolescents and young adults of both sexes, rural residents, and fall prevention for those older than 60 years. While existing MVC prevention programs do not specifically target SCI, programs that focus on seat belt use, drinking and driving, and risk-taking behaviours, may indirectly reduce the incidence of SCI (18, 19).

A recent case-control study from Australia found an association between SCI and occupants of non-sedan vehicles (sport utility vehicle, passenger vans, utility vehicles) involved in single vehicle rollover crashes in rural areas (OR=10) (20). It may be feasible to replicate this research in Alberta using data from the Alberta Trauma Registry and the Office of the Medical Examiner to validate the results. By implication, attention should focus on specific interventions for the prevention of this type of injury.

This present study clearly demonstrated the need for ongoing follow-up care for persons with SCI. Health professionals in the community, such as family physicians or physical therapists, who will provide much of this care may not be familiar with the lifelong medical and psychological needs that are specific to a person with SCI. The provision of current, evidence-based information packages tailored to such health providers is an important service that could be developed by SCI specialists. The proposed Rick Hansen Spinal Cord Injury Registry (RHSCIR) (21) may be a vehicle to facilitate the identification of health providers who care for patients with SCI in the community and to disseminate information to them.

Because individuals with SCI may tend to negate need for ongoing contact with a physician, they may be unwilling to take the time to come back for regular evaluations. A follow-up system involving reminder cards or phone calls from family physicians, outreach services, and/or peer support groups might encourage persons with SCI to have annual physical examinations.

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Appendix A

Search Strategies for the literature reviews

A.1 Search strategies for the literature review on 'Epidemiology of SCI'

Medline (Ovid): 1966 – August 2003 (N=313)

1 Exp *spinal cord injuries/epidemiology, mortality or exp *paraplegia/ epidemiology, mortality or *quadriplegia/ epidemiology, mortality
2 Exp Canada or exp United States or Australia or New Zealand or Austria or Belgium or Finland or France or Germany or exp Great Britain or Iceland or Ireland or Italy or Netherlands or Portugal or exp Scandinavia or Spain or Switzerland
3 1 and 2
4 Limit to English language
5 Limit to human

Premedline (Ovid): 2002 – September 2003 (N=8)

1 spinal cord injury/ or spinal cord injury [keyword] or paraplegia/ or paraplegia [keyword] or quadriplegia/ or quadriplegia [keyword]

CINAHL (Ovid): 1982 – August 2003 (N=23)

1 Exp *spinal cord injuries/epidemiology, mortality, risk factors or *paraplegia/epidemiology, mortality, risk factors or *quadriplegia/epidemiology, mortality, risk factors
2 Exp Canada or exp United States or Australia or New Zealand or Austria or Belgium or Finland or France or Germany or exp Great Britain or Iceland or Ireland or Italy or Netherlands or Portugal or exp Scandinavia or Spain or Switzerland
3 1 and 2

EMBASE (Ovid): 1988 – August 2003 (N=50)

1 Exp spinal cord injury/epidemiology or paraplegia/epidemiology or quadriplegia/epidemiology
2 Exp Canada or Exp United States or Australia or New Zealand or Austria or Belgium or Finland or France or Germany or exp United Kingdom or Ireland or Italy or Netherlands or Portugal or exp Scandinavia or Spain or Switzerland
3 1 and 2
4 Limit to English language
5 Limit to human

A.2 Search strategies for the literature review on 'Re-hospitalization and utilization of physician services following SCI'

Medline (Ovid): 1966 – August 2003 (N=13)

1 Exp *spinal cord injuries/ or exp *paraplegia/ or *quadriplegia/
2 Patient readmission/ or exp ambulatory care/ or exp physician's role/ or exp physicians/
3 1 and 2
4 Limit to English language

Premedline (Ovid): 2002 – September 2003 (N=8)

1 spinal cord injury/ or spinal cord injury [keyword] or paraplegia/ or paraplegia [keyword] or quadriplegia/ or quadriplegia [keyword]

HealthSTAR (Ovid): 1975 – June 2003 (N=0)

1 Exp *spinal cord injuries/ or exp *paraplegia/ or *quadriplegia/
2 Patient readmission/ or exp ambulatory care/ or exp physician's role/ or exp physicians/
3 1 and 2
4 Limit to English language
5 Limit to nonmedline

CINAHL (Ovid): 1982 – August 2003 (N=20)

1 Exp *spinal cord injuries/ or *paraplegia/ or *quadriplegia/
2 Readmission/
3 1 and 2

EMBASE (Ovid): 1988 – August 2003 (N=24)

1 Exp *spinal cord injury/ or *paraplegia/ or *quadriplegia/
2 Patient readmission
3 1 and 2
Limit to English language

A.3 Search strategies for the literature review on 'Cost of SCI'

Medline (Ovid): 1966 – August 2003 (N=154)

1 Exp spinal cord injuries/ or exp paraplegia/ or quadriplegia/
2 Exp health care costs/ or cost and cost analysis/ or health expenditures/
3 Exp spinal cord injuries/economics or exp paraplegia/economics or quadriplegia/economics
4 (1 and 2) or 3
5 Limit to English language

Premedline (Ovid): 2002 – September 2003 (N=8)

1 spinal cord injury/ or spinal cord injury [keyword] or paraplegia/ or paraplegia [keyword] or quadriplegia/ or quadriplegia [keyword]

HealthSTAR (Ovid): 1975 – June 2003 (N=3)

1 Exp spinal cord injuries/ or exp paraplegia/ or quadriplegia/
2 Exp health care costs/ or cost and cost analysis/ or health expenditures/
3 Exp spinal cord injuries/economics or exp paraplegia/economics or quadriplegia/economics
4 (1 and 2) or 3
5 Limit to English language
6 Limit to nonmedline

CINAHL (Ovid): 1982 – August 2003 (N=41)

1 Exp spinal cord injuries/ or paraplegia/ or quadriplegia/
2 Exp health care costs/ or costs and cost analysis/
3 1 and 2

EMBASE (Ovid): 1988 – August 2003 (N=100)

1 Exp spinal cord injury/ or paraplegia/ or quadriplegia/
2 Exp health care cost/ or cost/
3 1 and 2
4 Limit to English language

EconLit (SilverPlatter): 1969 – June 2003 (N=2)

1 Keyword search: 'spinal cord injur*' or 'paraplegia' or 'quadriplegia'

Appendix B

Validation of the search criteria for Alberta Health and Wellness data sources

To determine the most appropriate ICD-9-CM codes to identify SCI cases from the Alberta Health and Wellness data sources, a chart review was conducted of a random sample of patients from the Capital Health Authority (CHA). Two searches were conducted of the CHA inpatient (IP) and emergency department (ED) electronic databases for the period of April 1, 1998 to March 31, 1999. The first search identified patients coded with ICD-9-CM codes 806.x or 952.x (SCI codes). The second search identified patients with 805.x or 839.0 – 839.59 or 953.x codes (non-SCI codes), who did not have an SCI code. To avoid double counting patients who came through the ED prior to hospital admission, the search of the ED database was restricted to patients who died in the ED or who were discharged home. The search of the IP database was restricted to the six acute care hospitals within the CHA.

A total of 860 patients were identified. One hundred had SCI codes and 760 had non-SCI codes. The breakdown by code and type of admission is shown in Table B.1.

Table B.1. Patients with SCI and non-SCI codes admitted to the CHA (n=860).

Type of admission / ICD-9 code	806.x	952.x	805.x	839.0 – 839.59	953.x	Total
IP	44	21	340	13	12	430
ED	0	35	352	17	26	430
Total	44	56	692	30	38	860

For the non-SCI codes, 20 (5.1%) ED patients and 20 (5.5%) IP patients were randomly selected. For the SCI codes, a random sample was selected of 10 patients from each of the codes and type of admission (30%). A total of 70 charts were reviewed to confirm the documentation of newly diagnosed traumatic SCI, as determined by the presence of neurological damage or absence of motor and/or sensory function during the ED or hospital visit. Table B.2 shows the breakdown by site and type of admission.

Table B.2. Sources of randomly selected charts (n=70).

Type of admission / Site	UAH	RAH	Grey Nuns	Miseri-cordia	Sturgeon	Leduc	Total
IP	30	8	0	1	1	0	40
ED	11	6	6	4	2	1	30
Total	41	14	6	5	3	1	70

Of the 70 cases, 3 (4.3%) patients with SCI codes were excluded from the analysis because their visits were return visits for previously diagnosed SCI. Of the remaining 67 cases, 18 (26.9%) had SCI and 49 (73.1%) did not. Of the 27 patients with SCI codes, 17 were confirmed with SCI and they were all inpatients. Of the non-SCI codes, 39 patients had no diagnosis of SCI. Two cases were miscoded. One patient was assigned an SCI code but sustained an injury to the brachial plexus, which should have been coded 953.x. One patient was assigned a non-SCI code, but was diagnosed with conus medularis, which is considered a SCI.

Sensitivity, positive predictive value (PPV), and negative predictive value (NPV) were calculated using a weighted analysis to adjust for the different proportion of cases that were selected from the SCI and non-SCI code groups (30% for SCI; 5% for non-SCI) (Table B3).

Table B.3. Results of the chart review (weighted values).

ICD-9 code / SCI status	SCI	No SCI	Total
806.x & 952.x	17	10	27
805.x & 839 & 953.x	6	234	240
Total	23	244	267

Sensitivity = 73.9% (95% CI: 53.5%, 87.5%)
PPV = 63.0% (95% CI: 44.2%, 78.5%)
NPV = 97.5% (95% CI: 94.7%, 98.8%)

Sensitivity (73.9%) is interpreted as the proportion of people with a confirmed SCI who were coded with an SCI code. The PPV (63.0%) is the proportion of people who were assigned an SCI code and, in fact, had a confirmed SCI. The NPV (97.5%) is the proportion of people without a confirmed SCI who were assigned one of the non-SCI codes. Based on the results of this chart review, using ICD-9-CM codes of 806.x and

952.x, we would overestimate the true number of SCIs by 17% (95% CI: 7%, 37%). We felt this was an acceptable margin of error, especially as the use of these codes would allow for comparisons with other studies that used these codes. Therefore, patients who were assigned these codes were included in the study.

Also based on the results of the chart review, patients who were seen in the ED but were subsequently discharged without being admitted to hospital were excluded as SCI cases. From the chart review, there were no patients with SCIs who fell into this category (Table B4).

Table B.4. Patients with SCI codes only (n=27).

Type of admission / SCI status	SCI	No SCI	Total
IP	17	1	18
ED	0	9	9
Total	17	10	27

Appendix C

Validation of inclusion of short stay trauma centre visits

To validate the inclusion of short stay (7 days) admissions in this study, a chart review was conducted in the Capital Health Authority. Patients were included if they met the following criteria:

1. Admitted as an inpatient to a trauma centre,
2. Admitted between April 1, 1998 and March 31, 1999,
3. An ICD-9-CM code for SCI (806.x or 952.x),
4. Length of stay of 7 days or less,
5. Discharged home.

A total of 13 cases were identified. Of these, 12 (92.3%) demonstrated neurological symptoms or radiologic evidence of SCI. The length of stay in a trauma centre ranged from 1 to 6 days. Based on this review, patients with an ICD-9-CM code for SCI who were admitted to a trauma centre for at least 1 day were included in the study.

Appendix D

Case Ascertainment from the Office of the Medical Examiner

Files from the Office of the Medical Examiner were reviewed for the period April 1, 1997 to March 31, 2000. Cases were included if there was an autopsy or external examination report with specific mention of damage to the spinal cord, if the immediate cause of death on the death certificate was a fractured cervical spine, or if paralysis was noted in the emergency medical services, emergency department or hospital record. A total of 1,053 records were examined. Of these, 69 deaths involved a SCI.

Determination of SCI

Autopsy	15 (21.7%)
Fractured cervical spine	39 (56.5%)
Paralysis in chart	11 (15.9%)
Transection of spine	4 (5.8%)

Etiology of SCI

MVC	44 (63.8%)
Pedestrian	7 (10.1%)
Intentional	6 (8.9%)
ATV/snowmobile	4 (5.8%)
Fall	3 (4.3%)
Farm vehicle	2 (2.9%)
Air crash	2 (2.9%)
Gunshot (unintent.)	1 (1.4%)

Appendix E

ICD-9-CM codes for diagnostic categories for Inpatient database and Physician claims

Diagnostic category	*ICD-9-CM codes*
Infections and parasitic diseases	011.x – 139.x, V01.x – V06.x, V73.x – V75.x
Endocrine and metabolic diseases	240.x – 279.x, V77.x
Mental disorders	290.x – 319.x, V40.x, V62.8x, V71.0x, V79.x
Nervous system & Sense organ diseases	320.x – 389.x, V41.x – V41.6, V80.0 – V80.3
Circulatory diseases	390.x – 459.x, V81.0 – V81.2
Respiratory diseases	460.x – 519.x, V81.3 – V81.4
Digestive diseases	520.x – 579.x, V47.3
Genitourinary diseases	580.x – 629.x, V41.7 V81.5 – V 81.6
Skin and related diseases	680.x – 709.x, V82.0
Musculoskeletal diseases	710.x – 739.x, V82.1 – V82.3
Symptoms and ill-defined conditions	780.x – 799.x
Injuries	800.x – 995.x
Complications of medical care	996.x – 999.x
Rehabilitation & aftercare	V45.x, V46.x, V51.x – V56.x, V57.x, V58.x, V63.x, V66.x, V67.x
Well-patient care	V70.x, V72.x
Other includes:	
Neoplasm	140.x – 239.x, V76.x
Blood diseases	280.x – 289.x, V78.x
Pregnancy & perinatal conditions	630.x – 677.x, 760.x – 779.x, V20.x – V39.x, V61.7
Congenital anomalies	740.x – 759.x

Appendix F

ICD-9-CM codes for secondary complications

	Inpatient database	Physician claims
Urinary tract infection	599.x – 599.0	599.x
Decubitus ulcer	707.x – 707.0	707.x
Septicemia	038.x, 998.5x	
Pneumonia	480.x – 486.8, 487.0	480.x – 487.x
Venous thromboembolism	451.x	
Pulmonary embolism	415.1 – 415.19	
Depression	296.x, 300.4, 309.x, 311	296.x, 300.4, 309.x, 311, V79.0

Appendix G

Calculation of adjusted Alberta costs for hospital visits

G.1 Background

In Alberta there is no cost list that provides the detail required to calculate hospital costs for Albertans who sustained a spinal cord injury. The Alberta Health and Wellness publication *Health Costing in Alberta, 2001 Annual Report* (2001) provides some information, but the costs listed are the **average** cost per visit per Refined Diagnostic Related Group (RDRG). Average costs do not allow for the calculation of individual cost per visit based on length of stay. Such detail is required to provide a picture of the actual hospital costs rather than the average hospital costs. The following costing method was developed that combines information from a number of available sources and enables a calculation of adjusted Alberta costs for hospital visits.

G.2 Elements of the Costing Formula

The components used to calculate adjusted Alberta costs for hospital visits are:

1. Refined Diagnostic Related Group (RDRG): RDRG refers to a patient classification system that provides a way of describing the types of patients admitted to hospital for treatment. RDRGs work by taking ICD-9-CM codes and grouping them into clinically meaningful patient categories that have similar hospital resource requirements. RDRGs further divide patients in most diagnostic categories according to levels of severity defined by complications and co-morbidities, which would be expected to affect the amount of hospital resources used. Each hospital visit is assigned a RDRG grouper, which is part of the separation abstract and is collected in the Canadian Institute of Health Information (CIHI) Inpatient database. RDRGs were included in the data provided by Alberta Health and Wellness.
2. Length of Stay: Length of stay for each hospital visit is included in the CIHI Inpatient database.
3. Average Length of Stay for Typical Cases [Alberta]: This information is available for each RDRG grouper and is published in *Health Costing in Alberta, 2001*

Annual Report (2001). Information is based on patients admitted to Alberta hospitals during fiscal year 1997-98.

4. Costs: Costs for hospital visits are taken from the *Cost List for Manitoba Health Services* (1999). This cost list is designed to link directly to data routinely generated by administrative records, including hospital discharge abstracts. The report provides province-wide cost estimates of inpatient hospital care in Manitoba. It is based on average costing, which starts at the top with total inpatient expenditures and then divides these by a measure of total patient services. The inpatient cost list classifies cases into RDRGs. Costs are based on patient admissions during fiscal year 1993-94.
5. Marginal Cost per Day: The marginal cost is the cost of an additional day of care in hospital after the trim point of the average length of stay has been reached. The trim point is the point after which LOS is determined to be abnormally long and any additional days are classified as outlier days. Marginal costs are taken from the *Cost List for Manitoba Health Services* (1999).
6. Index Factor to convert Manitoba costs to relative Alberta costs: Relative Alberta costs are calculated using an index factor based on the costs per weighted case for Alberta and Manitoba taken from the *National List of Provincial Costs for Health Care: Canada 1997/8* (2000). The cost per weighted case for each province was estimated by dividing the total inpatient cost by the total weighted cases for all participating hospitals. Inpatient expenditures were derived from the CIHI Annual Hospital Survey in accordance with a national chart of accounts found in the CIHI Management Information System guidelines.

   The index factor is calculated by dividing the cost per weighted case in Alberta ($2842) by the cost per weighted case in Manitoba ($2301). The index factor is 1.23.
7. Consumer Price Index: To account for inflation, costs are converted from 1993 (July) to 2002 (July) dollars using the Bank of Canada's consumer price index. The inflation factor is 1.18.

G.3 Calculation of Adjusted Alberta Costs

Below is a sample of information found in the *Cost List for Manitoba Health Services* (1999) for RDRG #0010 – Craniotomy except for trauma with no complication or comorbidity (Table G.1). Table G.2 is information from *Health Costing in Alberta, 2001 Annual Report* (2001) for the same RDRG grouper.

Table G.1. RDRG 0010 *Craniotomy except for trauma with no CC* (Manitoba)

Average LOS for typical cases	Trim	Cost per case	Average cost per day	Marginal cost per day
6.3 days	16.5 days	5366	$852	$594

Table G.2. RDRG 0010 *Craniotomy except for trauma with no CC* (Alberta)

Average LOS for typical cases	Trim	Average cost per visit
6 days	18 days	$8,311

The calculation of hospital costs for a patient whose LOS is at or below the Average LOS for a typical case in Alberta is:

Adjusted Alberta $ = (LOS * A) * D * E

where,

LOS = Length of stay per visit (from the CIHI Inpatient database)

A = Average Cost per Day [Manitoba] (from *Cost List for Manitoba Health Services)*

B = Average LOS [Alberta] (from *Health Costing in Alberta, 2001 Annual Report*)

C = Marginal Cost per day [Manitoba] (from *Cost List for Manitoba Health Services*)

D = Index factor to convert Manitoba costs to relative Alberta costs (factor = 1.23).

E = Inflation factor to convert from 1993$ to 2002$. The factor is 1.18.

The calculation for a patient whose LOS is more than the Average LOS for typical cases in Alberta is:

Adjusted Alberta $ = ((B * A) + (LOS – B) * C)) * D * E

G.4 Examples

Assume a patient was grouped into RDRG 0010 (Craniotomy).

Table G.3. RDRG 0010 Craniotomy except for trauma with no CC (from Alberta & Manitoba cost lists)

Average LOS (Alberta)	Average Cost per day (Manitoba)	Marginal Cost per day (Manitoba)
6 days	$852	$594

Case 1: LOS=5 days (within the average length of stay for Alberta)

*Cost of hospital visit = LOS * Average cost/day= 6 * $852 = $5,112*

To calculate relative Alberta costs, multiply by the index factor of 1.23.

Relative Alberta cost (1993$) = 1.23 $5,112 = $6,288*

To convert this from 1993 dollars to 2002 dollars, use the inflation factor of 1.18.

*Adjusted Alberta cost (2002$) = $6,288*1.18 = $7,420*

Case 2: LOS=20 days (14 days above the Alberta average length of stay)

*Cost of hospital visit = ((6 days * 852) + (20 days – 6 days) * 594)*
=5,112 + 8,316
= $13,428

Relative Alberta cost (1993$) = 1.23 $13,428 = $16,516*

*Adjusted Alberta cost (2002$) = $16,516*1.18 = $19,489*

Appendix H

Multivariable regression model for estimating the predicted health care costs

Variables entered into the final model

Age	Age at injury	continuous
Sex		0=female; 1=male
Case/Ctl	Case or control	0=SCI case; 1=control
YR26	Year of injury	0=Year 1; 1=years 2 – 6
SEV2	Severity of injury (for case & control clusters)	0=incomplete; 1=complete
SevXcase	Interaction term between Severity of injury and Case or control	
YrXcase	Interaction term between Year and Case or control	
SevXyr	Interaction term between Severity and Year	
SvXyrXcs	Interaction term between Severity and Year and Case or control	

Coefficients

Variables	Unstandardized Coefficients	Standard Error	t	Sig.
Constant	41645.519	1052.060	39.585	.000
Case/ctl	-41925.653	1046.662	-40.057	.000
Age	52.617	7.629	6.897	.000
Sex	-.446.936	345.476	-1.294	.196
Yr26	-39651.113	1046.662	-37.883	.000
YrXcase	39243.714	1146.561	34.227	.000
SEV2	79881.392	2225.014	35.902	.000
SevXcase	-80428.163	2436.409	-33.011	.000
SevXyr	-76882.915	2436.409	-31.556	.000
SvXyrXcs	77340.231	2668.952	28.978	.000

Dependent Variable: Total costs

Model Summary

Model R	R Square	Adjusted R Square	Std. Error of the Estimate
.632	.400	.399	13170.207

ANOVA

	Sum of Squares	df	Mean Square	F	Sig
Regression	968087857948.144	9	107565317549.794	620.136	.000
Residual	1453200582802.908	8378	173454354.596		
Total	2421288440751.052	8387			